Beyond the Medical Admission:
Social Pathways into Nursing Homes

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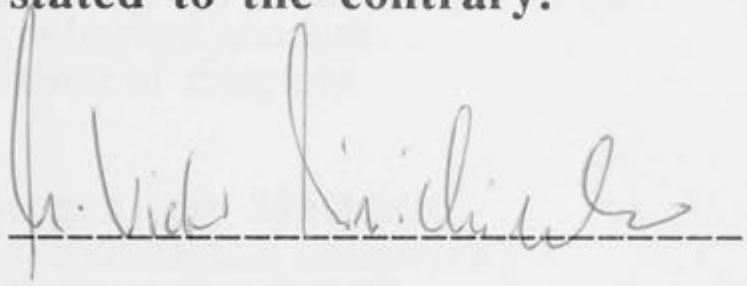

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Acknowledgment

Sharing and generating ideas is the ultimate purpose of research. Without a collective consciousness intellectual work has no meaning. To claim that this thesis belongs to me is to ignore how the many ideas and pages were put together and the contributions others have made to my study.

First and foremost, I owe much to my grandfather. Like many other young people, I was too busy to give my grandfather much time. It was only after he died that I felt his absence. This thesis is in his honour; my attempt to understand the life of older people and to listen to their stories.

During the last five years, my supervisor, Hal Kendig, has provided much guidance and encouragement. Often such support extended beyond academic work. Heather Gardner, Rosalie Aroni and Loris Alexander have provided valuable assistance at critical times. In particular, I wish to express my gratitude to Loris Alexander. She was determined to see my thesis completed. Although I mention his name last, my companion, Terrence saw me through the more difficult stages of my student career. Together we were able to break new ground in Australian immigration policy. I was granted permanent residency by the Commonwealth Department of Immigration and Ethnic Affairs on the basis of my relationship. The recognition of this basic human right means that I can live with my companion and in the country I have come to love.

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Abstract

Using a multi-method approach and combining micro and macro levels of theories, this thesis examines the pathways which aged residents and their next-of-kin have taken to arrive at the doorsteps of nursing homes. The analysis focuses on the active social processes and the subjective meanings individuals construct about their experiences of entering and living in nursing homes. Data sources include in-depth interviews, participant observation and questionnaires with aged residents, their next-of-kin and nursing home directors.

There are several steps in the decision making process. There is not only the question of making the decision to seek nursing home care, but also one of selecting the nursing home. The results show that (1) most residents were excluded from the decision making process; (2) family members, along with health professionals, are seen as influential participants in the decision making process; (3) the perceptions of managing/not managing, entitlements and obligations played a crucial role in seeking and determining involvement in the decision; and (4) participation in the decision making process is an important predictor of subjective well-being.

The thesis also reported on the contacts that the elderly in nursing homes have with family and friends. Like their North American and English counterparts, the Australian aged living in nursing homes (1) are not generally forgotten by their family and friends; (2) the childless residents are not without visitors; (3) who comes to visit varies with the marital status of the residents;

and (4) relationships can best be understood in the context of the history of the relationship and perceptions of family ties. The thesis also exposed a number of administrative practices which could impact on the automony and rights of the older person entering a nursing home.

CHAPTER 1

Introduction

This thesis is a sociological study of the processes involved in older people entering and living in nursing homes. The analysis pursues two lines of inquiry. The first asks questions about the social pathways through which older people reach the doorsteps of nursing homes. It looks at the ways in which older people, their families and health professionals go about making decisions to seek formal residential care. Specifically, it unravels the issues associated with the decision making process, the actors in this process, their views on what motivated the decision, and the actions or inactions of the older person vis-a-vis family members and health professionals.

The second line of inquiry looks at the social world of residents. The nature and quality of the contacts older people in nursing homes have with family and friends are explored. Too little attention has been directed to how institutionalisation affects interaction between the resident and her[1] informal network. What changes do aged persons feel in their relationships with family and friends as a result of placement in a nursing home?

Both of these topics are important areas of research given that entering a nursing home is an emotionally charged and complex issue for the aged and their families, and that in Australia demographic trends probably will necessitate a greater proportion of people confronting this decision (Kendig and McCallum, 1986). For most older people, moving into a

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(1) As the majority of nursing home residents are women, the female gender is used throughout the text.

nursing home is perceived as a decisive change: the 'last stop' the individual will experience in life (Tobin and Lieberman, 1976). For family members, the decision to institutionalise an aged person invites feelings of grief that can be even more traumatic than when the older person dies (Cath, 1972). It may signal also that society is moving away from the traditional value of a family looking after its own members. An understanding of the ways in which people make decisions to seek nursing home care and the social consequences of institutional living can assist policy makers in developing strategies that will alleviate some of the fears associated with living in a nursing home.

A Conceptual Approach to Study Human Action

While the institutionalisation of the aged has been a popular topic of research in Australia (for a review see Minichiello et al., 1988) and overseas (see Thomson, 1983; Wingard et al., 1987), the studies in this area have had significant shortcomings. The voice of the aged and other key actors is seldom heard in researchers' accounts of why some older people use nursing homes. Much of the data in these studies are collected by either reviewing the medical file or administering a questionnaire to nursing home directors or physicians (Wilkin and Hughes, 1987). The choice of this methodological strategy may be partly due to the difficulties of interviewing frail and confused aged people living in institutions (Yordi et al., 1977), and difficulties of locating and gaining access to aged persons in institutions or their relatives living in the community (Gibson and Aitkenhead, 1983; Lee and Finney, 1982; Rowland et al., 1984). However, it also reflects the unwillingness of many researchers to apply procedures which would examine the perceptions and

experiences of elderly people themselves (Johnson and Cooper, 1983; Marshall, 1979,1981; Russell, 1981).

This thesis listens to how older people and their close kin relate the decision making process to their life stories (Johnson, 1976; Pulmer, 1983). The approach minimizes the chances of seeing the decision to seek nursing home care solely in terms of the physical decline associated with ageing, and focuses on the association between people's personal and social histories and their current situation. The study also examines the views of nursing home directors in order to comprehensively identify possible players in the decision making process. The aim is to understand interpersonal negotiations in decision making process. Only by taking a full account of the interactions between older people, close kin, and health professionals can we shed light upon the social dynamics behind the decision making process.

Most of the current literature reports on the objective difficulties that old people face (eg., failing health, inadequate resources) and how these place them at risk of institutionalisation. Quantitative studies have related admission into nursing homes to the availability of long-term beds or the lack of alternative care in the community (Howe et al., 1986); the absence, inability or unwillingness of families to aid the older person in independent living (Branch and Jette, 1982; Doty, 1986; Stone et al., 1987); or sociodemographic characteristics of the older person or the geographical distance of kin (Liu and Manton, 1983; Shapiro and Tate, 1985; Soldo and Manton, 1985). What is often left out of these studies is the importance of meaning, the primacy of experience and the intentionality of human beings.

Other researchers have studied institutionalisation from a political economy or Marxist perspective. These studies examine how the dependency of the aged is socially constructed by economic forces and relations in capitalist societies. They also focus on the underlying political convenience promoting institutionalisation rather than the meanings people attach to their own actions and the actions of others (Dowd, 1984; Phillipson, 1982; Walker, 1980, 1981).

Both of these approaches take a macro view of individuals as being passively moulded by social structures. They do not take into account individuals' capacities for actively creating and negotiating their own social world, and neglect the subjective experience of old age (Russell, 1981). While the influence of macro factors is valuable in understanding experiences in old age, social theorists also need to understand the ways in which people perceive their world and the meanings through which they interpret their experience (Johnston, 1972). Indeed, the recovery of the hermeneutic tradition is one of the most significant occurrences in recent trends of development in the social sciences (Giddens, 1987). There is a growing interest amongst social gerontologists in examining the views of older people as the prime focus of social analysis, and seeing people as capable of understanding the conditions of their own actions (Brown et al., 1986; Wilkins and Hughes, 1987).

A symbolic interactionist perspective is employed in this study to explore, through the words of the key actors, the major themes that emerge in people's accounts of entering and living in a nursing home. Symbolic interactionism provides a framework by which to study interaction patterns between residents and their families in the decision to seek nursing home care. This approach is tied to the theoretical tradition of the looking glass self

concept (Cooley, 1964), the definition of the situation (Thomas and Znaniecki, 1927), the social construction of reality (Berger and Luckmann, 1966) and the self process (Mead, 1934). Proponents of the interactionist approach assert that people's actions are contingent on the meanings attributed to them.

Meanings of situations are derived from or arise out of the social interaction that people have with others. These meanings are modified through an interpretative process as people deal with the situations in which they find themselves (Blumer, 1969). In this context, human action is not fully determined by social forces. People are active, knowledgeable and intentional agents who create and interpret their social world, and this in turn, influences their actions or inactions. Essential to the symbolic interactionist perspective is 'the view that human beings construct their realities in a process of interaction with other human beings' (Russell, 1981:64). The focus of inquiry is on how people account for their line of action and the capturing of the meanings which actors attach to their experiences.

The analysis in this thesis focuses on actions, interactions, and subjective meaning of aged people and others involved with the application and admission process. The task is to understand the point of view of the informants and to see them as intentionally making sense of that point of view (Barritt and Suransky, 1982). For this reason, this research is not about 'studying people' but about 'learning from people' and doing research <u>with</u> people. The reader is invited to take part in a dialogue between the researcher and his respondents and to reflect on the meaning that a particular world holds for the respondents. People's interpretations of their experiences is the very core of the analysis. In the words of Clifford Geertz:

> Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretative one in search of meaning (1973:5).

Of course, a clear understanding of people's situations involves a recognition of broader sociological factors other than the influence of perception on action. Symbolic interactionism has been criticised for failing to take some overview of the influence of the overall organisation of society on individuals (Cuff and Payne, 1984). Recent theorists (eg., Giddens, 1987) have argued that action and structure can be used in a complimentary way to describe and explain human behaviour. Symbolic interactionism allows us to study how individuals act as purposive reasoning beings, while a macro perspective allows us to take into account how the social organisation of society provides a medium for interpretative agents to organise their activities. While this study primarily stresses the importance of investigating social action from the standpoint of the actors involved, it also examines the influence of social structure on individual action. The interrelationship between action and structure is studied using several methodological approaches. Qualitative methods are used to identify the micro processes by which people give meaning to their actions. Quantitative methods are used to illustrate the influence of structure on patterns observable in a diversity of social contexts.

The rest of this chapter examines residents who according to government policies could be cared for in the community but are occupying a nursing home bed. It outlines a sociological account for why these older people use nursing home care. The main concepts found in the literature on

institutionalisation are reviewed, while leaving the detailed examination of particular aspects of the micro and macro social processes to later chapters.

The Appropriateness of 'Inappropriate' Placement

The stated objectives of nursing homes are to provide services for physically and mentally handicapped people who require nursing care and supervision. However, in the past two decades, the substantial self-care capacities on the part of many residents has been documented in both the overseas and Australian literature. Commenting on the use of nursing homes in the United Kingdom, Townsend reports:

> Evidence continues to be published from different parts of the country testifying to the non-frailty of a substantial proportion of the residents. Let me illustrate from a report published in 1980 (in Britain). Booth arranged for detailed questions to be put about ability for self-care, continence and social integration of the residents in one local authority. Over one-fifth (22.1 per cent) of residents in nursing homes in Sheffield were assessed as requiring care and support of a degree which rendered them substantially dependent on residential staff. On the other hand, a much larger proportion of residents (37.3 per cent) were rated as largely independent in their personal functioning within the home; and bearing in mind the possibility that the method of assessment may have tended to over-predict the extent of dependency, then the estimate is likely to underrepresent the ratio of active and able residents in the homes (1981:16).

Australian and other overseas studies support Townsend's conclusion that a significant number of patients in nursing home beds do not require institutional care. A Tasmanian study on the physical and mental disability

of patients in nursing homes found that between 27 to 37 per cent of them could be cared for in hostels or in their own homes. These residents did not require help with feeding, grooming, toileting, walking, dressing or transferring to and from a chair or a bed (Department of Community Services, 1984). A study in three Australian states found that between 10 to 20 per cent of the residents in nursing homes require less than one hour of nursing care per day (Rhys-Hearn and Hearn, 1986). These residents received only low level care with showering and the provision of medication; this type of help often reflects the senior staff's requirement that all residents be supervised in these activities. Similarly a national study of handicapped persons (Australian Bureau of Statistics, 1981) found that of the 91,500 persons of the total elderly populations living in institutions, 8,900 of them reported no handicap and 7,700 reported only mild or moderate handicaps: together these less likely candidates for institutionalisation comprise 19 per cent of the total residents (Gibson and Rowland, 1984).

Overseas studies report similar levels of apparently 'inappropriate' placement in nursing homes (Doobov, 1980). Fourteen American studies indicate that 20 to 40 per cent of the nursing home population could be cared for in the community if low levels of care were available (Congress of the United States Congressional Budget Office, 1977). A British study of 6947 nursing home patients found that almost a quarter of the residents were largely independent in their personal functioning within the home, capable of performing the basic skills of daily living, mentally alert and socially competent (Booth et al., 1983). Repeating successive health evaluation of residents living in nursing homes over a four year period, Booth (1985)

found no evidence that the introduction of geriatric team assessments in intervening years was screening out the less dependent clients. The result of this study supports the view that admission into nursing homes may be influenced by factors other than the health needs of old people.

Functional ability is thus a limited predictor of placement in a nursing home. Researchers who attempt to differentiate users of nursing homes from non-users find that health status is not the sole determinant of entering institutions (Vicente et al., 1979). For instance, a study conducted in the United States estimated that about 33 per cent of the clients receiving care in the community had limitations which equalled or exceeded those of the elderly living in institutions (State of Illinois, Department of Ageing, 1975). For almost every person over 65 years of age who enters an institution, there are two other elderly persons who live in the community who are homebound, with one out of four of the latter group severely incapacitated (General Accounting Office 1977; Kane and Kane, 1983). Another American study found that while more residents in nursing homes than in the community were severely impaired, the proportion of moderately impaired persons was very similar for both groups (Giele, 1981). The similarity at the middle range of dependency is worth noting, for it is in these cases where social factors may intervene in deciding whether or not a decision to seek institutional care will be sought. The majority of the handicapped elderly (82 per cent) in Australia live in private households. Even among those most at risk of being institutionalised -- the severely handicapped aged 75 and over -- a significant number live in the community (Gibson and Rowland, 1984).

A consistent message in government reports on nursing homes in both Australia and overseas is that between 15 to 20 per cent of residents are 'inappropriately' placed. Public attention on 'inappropriate' placement is partly due to government's attempts to curb the growth of public expenditure on nursing homes (Walker, 1981; Philips, 1987). In Australia, current policies are attempting to restrict admission to patients having impairments which unequivocally dictate nursing home care (Department of Community Services, 1986). However, these reports provide little insight into the reasons why the less dependent patients are not living in the community. While they clearly show that clinical evidence alone can not account for the placement of all residents living in nursing homes, they fall short of explaining why these residents have reached the doorsteps of nursing homes. There are few accounts of why an alternative path of care was not chosen by residents, their families and health professionals.

The purpose of this study is to delve more deeply into the issues associated with relying on nursing home care for those patients who do not necessarily satisfy clinical criteria for residency. For this reason, the sampling procedure was designed to identify residents who were admitted predominantly because of social rather than medical factors. As will be explained in chapter 2, this represents a special sample within the nursing home population. The study raises the following question: why did these residents enter a nursing home when from the point of view of government policies they are 'inappropriately' placed? It looks closely at the processes which lead to the decision to seek nursing home care and examines why the decision makers felt that the placement was an appropriate choice.

A Sociological Account of the Use of Formal Services

The medical model offers a simple explanation for why people use health services. According to this approach there is the 'straightforward recognition of illness which is then taken to doctors for expert diagnosis' (Davis and George, 1988:226). However, as Davis and George state:

> ...while much medically inspired literature operates with a model of human beings that takes rational illness behaviour to be the adoption of the biomedical model as the appropriate explanation for illness, and correct and prompt use of appropriate medical services, this can at best produce a partial explanation of how people actually get to see a doctor (1988:226).

Patients' rationality for using services may be different from that of the dominant medical form of rationality. Limitations of the medical rationality model have led medical sociologists to explore three interrelated social factors which may influence service use (Anderson and Newman, 1973). The first set comprises predisposing factors such as family attitudes, social structure and health beliefs. The second, enabling factors, include available family and community resources. The third set is need, which influences the individual's perception of illness. These factors can be used to show why individuals' demographic and social characteristics are related to their chances of using health services. While the individual may be predisposed to use health services, whether or not she actually does use them also depends on family and community resources. These can enable the person to cope with the situation or seek professional help. Finally, the individual (or those making decisions for the individual) must perceive some need for using health services.

In the social gerontological literature, researchers have focused on Anderson and Newman's 'enabling factors', the presence and availability of community and family support. These factors may help to explain why some older people are able to remain at home, while others are admitted into a nursing home. Family resources can be characterised as a factor delaying or assisting admission into a nursing home. When the analysis extends beyond a medical explanation, the role of family and community resources can be conceptualised, not as minor, but as major influences in the decision to seek formal care.

Australian and overseas studies show that admission into a nursing home occurs selectively from the total aged population (Howe and Preston, 1985; Wingard et al., 1987). Older persons who lack close ties are disproportionately represented among those admitted to institutions (Howe, 1979). Using cross-sectional data, researchers have shown that older people who have never married or had no children, and the very old who have outlived their family members, are more likely to be prematurely or inappropriately institutionalised (Butler and Newacheck, 1981; Branch and Jette, 1982; McAuley and Prohaska, 1982; Wingard et al., 1987). A large percentage of the nursing home residents who are never married lived in non-family arrangements prior to admission (Australian Bureau of Statistics, 1981). This group has the fewest alternatives when a crisis forces a change in living arrangement. Many live alone, or with others who are less likely than a spouse or child to assume responsibility in an emergency situation, thus necessitating institutionalisation (Johnston and Catalona, 1981). If having a family support network is a precondition for the dependent aged in

remaining in the community, then a significant number of aged persons are vulnerable to being placed in a nursing home. Using census statistics on single marital status and living alone as indicators of informal support, Rowland (1982) estimates that approximately 20 per cent of the Australian aged living in the community are at high risk of having to rely on residential services in the event of a crisis.

Many severely disabled older people are able to avoid or postpone institutionalisation because they receive social support from family or community services (Brody, 1981; Cantor, 1980; Branch and Jette, 1983; Gibson and Rowland, 1984; Kendig, 1986). These aged persons can become vulnerable to placement into an institution, not so much from a change in their health status, but from changes in the health status or marital status of their family members (Hing, 1981; Kraus et al, 1976). The presence of the family not only reduces the probability of admission to an institution, but also duration of stay. A national study conducted in the United States found that people in good health who entered nursing home because they had no family support had longer stays (3.2 years) than residents who had family support and were admitted because of poorer health (2.4 years) or for behavioural reasons (.7 years) (Hing, 1981).

Some researchers question whether the presence of family members can be interpreted as an insurance coverage that protects older people from using nursing home care. There exists tremendous variations in the types of support family members will, can or do offer their aged relatives. We cannot assume that family members are inherently or automatically supportive (Lee, 1984). The role and amount of support offered by families to an aged relative varies according to the past history of the

relationship, family composition, economic resources and other competing demands on family time and energy (Australian Council on the Ageing and Department of Community Services, 1985; Day, 1985; Kinnear and Graycar, 1984). Equally important are the older person's expectations about family support and their kin's perception of their entitlement to a full life (Day, 1986). This suggests that the availability of family support is partly dependent on how people define and negotiate entitlements and claims. The presence of predisposing and enabling conditions may place certain people at greater risk to use or not to use certain services, but their decision is also moulded by their perception of the situation.

The omission of human action may help explain why studies that have applied the Anderson and Newman framework to health and social service use have had limited success. While many of the predisposing and enabling factors are strongly related to service use at the bivariate level, these factors have been found to be not very important in multivariate analyses which control for competing influences (Coulton and Frost, 1982; Wan 1982a, 1982b; Wolinsky, 1978). At best, the variance of health service use explained by variables consistent with the Anderson and Newman model ranges from 9 to twenty percent. One might conclude from these findings that medical sociologists have exaggerated the importance of social factors in understanding why people use formal care. An alternative explanation is not that the conceptual measures do not fully encompass the ways in which an individual's sense of their situation influences their decision to use health services.

Criticising the researcher for placing too much emphasis on searching for structural influence on use of formal services, and reducing 'sociological' factors to variables dealing with socio-demographic measures, Mechanic notes:

> ...The determinants of help-seeking are part of a dynamic process involving responses and feedback from the environment and cannot be simply abstracted through general descriptors of the persons involved or their environments. In theory people with identical symptoms might behave differently depending on what is going on in their lives and on situational factors...(1979:393).

Including the Process View in the Sociological Account

An alternative way of looking at why some people use formal services and others do not is to study how people assess the advantages and disadvantages of seeking formal care. In extending the medical and sociological model to include the relevance of people's interpretations of their situations, it is important to study:

> ...the pre-consultation phases of illness behaviour and...the illness work done by the lay public as a necessary constituent part of the response to symptoms (Ford, 1986:144).

The experiences of old people entering and living in a nursing home can be shaped by how they see their situation, summon up plans of action, assess them and act upon them. Such actions, however, can only be understood in the context of the person's interaction with herself and others. The decision to live in a nursing home is seldom the product of only one individual but a social product that arises through the older person's

interactions with her family and health professionals. This allows us to view the decision making process as part of an organised set of actions with its own internal logic. Consultation with health professionals is only one possible end point (Ford, 1986). The decision making process contains many other possible courses of action, and as a result, the decision to use formal services is always uncertain (Sushman, 1965; Fabrega, 1973; Igun, 1979). The focus is to understand the perceptual processes which precede 'the medically rational act of consultation' (Ford, 1986:147), and the course of action by which it is decided that formal help is required. This helps to explain why the older person and her family's perception of need is an important predictor of the use of services (Coulton and Frost, 1982). For instance, the decision to enter a nursing home can be triggered by the family's perception of their inability to provide adequate support to cope with the burden of 'parent-caring' (Brody, 1985) or the older person avoidance of being seen as a burden (Day, 1985).

People's definition of situation and interpretation of need might be appropriately treated as antecedent factors in the Anderson and Newman model. However, quantifying need is not well suited for studying help seeking behaviour as the product of a definitional and interactional process. People become aware of a need, examine alternative solutions and weigh their options in terms of the costs and benefits of seeking formal care. These micro-level processes are dependent on interpersonal perceptions and situational influences. In contrast with the multivariate statistical analysis of large samples, a micro and qualitative analysis, as will be discussed in more detail in chapter 2, provides a basis to explore the dynamic process of individuals making sense of their <u>own</u> world.

By looking at how people give meaning to the events that precipitated entrance into the home, we can view the admission history as extending beyond the older person's medical condition. We can direct our study towards properties of situations as well as properties of individuals. In this context, the decision to use nursing home care is seen as the product of ongoing interactions between the older person, her family and health professionals. A retrospective analysis of the decision making process allows us to understand why people are socially selective in the ways they define need and explain their presence in nursing homes.

Outline of Chapters

The thesis aims to conduct a comprehensive analysis of the complex human issues surrounding the admission history of older people who have moved from their homes to live in a nursing home. The chapters apply the primary concepts developed in the first chapter. The decision making process is studied in terms of a negotiation process that takes place between the aged person, their families and professionals. Specific attention is given to the influence of people's perceptions on action and on the situations in which individuals find themselves. The latter provides individuals with an enormous range of possible courses of action. However, as the chapters show, the 'structural properties' of individuals are not seen as something that is external to human action. People are 'only able to carry out their day-to-day activities in virtue of their capability of instantiating those structural properties' (Giddens, 1987:61).

Chapter 2 outlines the methodological strategies adopted in the study to overcome the traditional tendency of only doing research based on either

quantitative or qualitative information. A rationale is presented for employing both qualitative and quantitative methods, and the process of data collection is reviewed. Such a methodological approach allows us to illustrate the interplay between micro and macro processes on human action.

A necessary first step in understanding the social processes involved in seeking formal care is to examine how people make sense of their pathways into nursing homes. Chapter 3 provides an analysis of how aged residents and their next-of-kin account for the decision to seek nursing home care. The chapter aims to find the logic in human action. The dominant themes that emerge from people's stories are presented and discussed. Although it is important to recognise that aged persons and their families take different paths to arrive at the doorsteps of nursing homes, and that these pathways are contingent upon personal and social resources, it is useful to begin the analysis with a composite picture of the dominant themes which emerge from people's stories. Despite the different circumstances surrounding their application, what they all have in common is that they are living in a home. Subsequent chapters search for differences in outlooks and experiences that emerge from people's accounts of seeking formal residential care.

Chapter 4 examines the influence of lay people's consultations with professionals on the decision to seek formal care. Studies which examine the actors in the nursing home decision illustrate that physicians play 'a significant first step' (Clough, 1981). The shortcoming of these studies is that they do not view decision making as a dynamic process that begins before a person enters the doctor's office. This chapter examines the role the aged person, her family and health practitioners play in the verdict to

obtain nursing home care, and the negotiations with family and professionals. People are not randomly selected to participate in the decision making process. The main focus is to identify the factors that account for why we find differences in who will be involved in the decision. The next chapter, 5, presents a typology of the older person's participation in the decision making process and examines why older people vary in their involvement in decisions to enter a nursing home. It explores the importance of perceptions of self-images and family support in relation to the older person's involvement in the decision making process.

Closely tied to the social processes of entering a nursing home is the question of how clients are selected by the nursing home staff. Chapter 6 looks at the criteria directors of nursing homes use to decide which applicants will be admitted. Entry into a nursing home thus is negotiated between an institution in need of patients and older people and their carers who require more formal support. The chapter highlights how nursing home directors can and do act intentionally and have reasons for doing so.

Whereas the above mentioned chapters discuss the factors that pull or push elderly people into nursing homes, the next two chapters, 7 and 8, look at the social world of residents. As the large majority of residents will spend the remainder of their lives in a nursing home, it is important to understand the types and kinds of continuing contact the older person has with family and friends. Chapter 7 addresses the issue of isolation of residents from their family and friends and examines differences between residents in visitors from their social networks. Chapter 8 examines how the attributes of the visitor and of the residents, and the nature of the relationship between them, influence visiting patterns, and whether moving into a nursing home

has affected the resident's relationships with family and friends. The discussion focuses on the social consequences institutionalisation has on family relationships.

Finally, chapter 10 reviews the contributions of this study and considers a number of ethical, quality of life and quality of care issues associated with the decision to obtain nursing home care. The ways in which current and proposed policies on institutional care may influence the lives of older people and their carers is also discussed.

CHAPTER 2

Integrating Methods

An important feature of the literature on ageing is its multidisciplinary nature. Given the diversity of theoretical backgrounds used to study ageing one would expect studies to include a variety of data collection strategies. Yet a recent survey of the Australian social gerontology literature published between 1980 to 1986 reveals that most researchers rely on questionnaires to collect the data. Of the 158 studies reviewed only five used a multi-method approach (Minichiello et al., 1988). The dominance of this method has lead some to criticise the Australian and overseas field of gerontology for being imbalanced towards descriptive and quantitative orientations (Marshall and Tindale, 1978; Russell, 1981). Research papers are filled with pages of numbers documenting statistically significant relationships between variables with little theoretical insight as to what accounts for these relationships. Some claim that the exclusively quantitative emphasis of research has been responsible for the slow theoretical development of gerontology and the sociology of ageing (Marshall and Tindale, 1978; Marshall 1981; Townsend, 1981).

In response to these criticisms a number of researchers are integrating several methods into their research designs. For instance, the Ageing and the Family Project at the Australian National University used a wide range of quantitative and qualitative methods to study the support provided and received by older people (Kendig, 1986). The results of such projects have led to an appreciation of a combination of qualitative and

quantitative research which views the two approaches 'as parallel and equal partners', each contributing different information (Kendig, 1986:13).

This chapter first explains why qualitative and quantitative methods were combined to study the decision to enter a nursing home and the relationship of residents with significant others. Secondly, it provides an overview of the research strategies used. Thirdly, it discusses specific data collection procedures in each of the five stages of the research.

Methodological Superiority - Is There Such a Thing?

Some scholars argue that certain methods, by virtue of their intrinsic qualities, are superior to other research methods (Becker and Geer, 1970). This argument has lead to a fierce, and often hostile, debate between proponents of different methodological approaches. Qualitative researchers have been criticized for using unscientific research techniques, taking on the role of the journalistic snooper and accepting impressionistic accounts. Those who use quantitative methods are condemned for reducing society to the fractionated level of a world expressed in statistical jargon (Sieber, 1973). Two methodological subcultures have been produced; one professing the superiority of deep, rich data, and the other the virtues of hard, generalizable data. These two approaches are often dichotomized as exclusive alternatives.

Some methodologists dispute the claim that qualitative or quantatitive research can be ranked in terms of the superiority of one above the other (Bouchard, 1976; Denzin, 1978). Instead, they argue that different kinds of information about society 'are gathered most fully and economically in different ways and that the problem under study properly dictates the methods of investigation' (Trow, 1970:33). The use of a combination of

methods will yield a more rounded, complete picture (Kendig, 1986). Too often researchers rely on a single method of inquiry or theoretical perspective irrespective of the topic. Although it is beyond the scope of this thesis to critique in detail the relationship between theoretical perspective and method, certain research techiques complement particular perspectives. The relationship between theory and method, however, should not always be taken for granted. Under certain circumstances variation from usual practice may facilitate rather than inhibit understanding. With this viewpoint in mind, Banks makes a plea for sociologists :

> ...to keep their minds open about their theories, their methods, their techniques. If there is anything prescriptive implied in it, it is probably this; that sociologists should seek to perfect whatever theoretical and research skills come most easily to them personally, that they should nevertheless make themselves conceptually familiar with those other skills which they do not find congenial but which other sociologists have striven to perfect, and that when tackling any theoretical, methodological or technical problem they should not only make plain the limitations of their own work as far as they can, but try to take advantage of the strengths of those other sociological works which have employed different methods from theirs (1979:577)

The researcher's theoretical stance should not be the only criterion used in choosing a method. Researchers can benefit by using convergent methodologies. In this way what is missed from the lens of one method can be caught and further tested from the lens of another method.

In order to select methods for this study, it was necessary to consider the kinds of methods and information which were relevant to the research topic at hand. How can the advantage of a given method over others be

evaluated and justified? Which sets of methods will be used? These questions formed the background to the selection of methods for studying the experience of old people in entering and living in nursing homes.

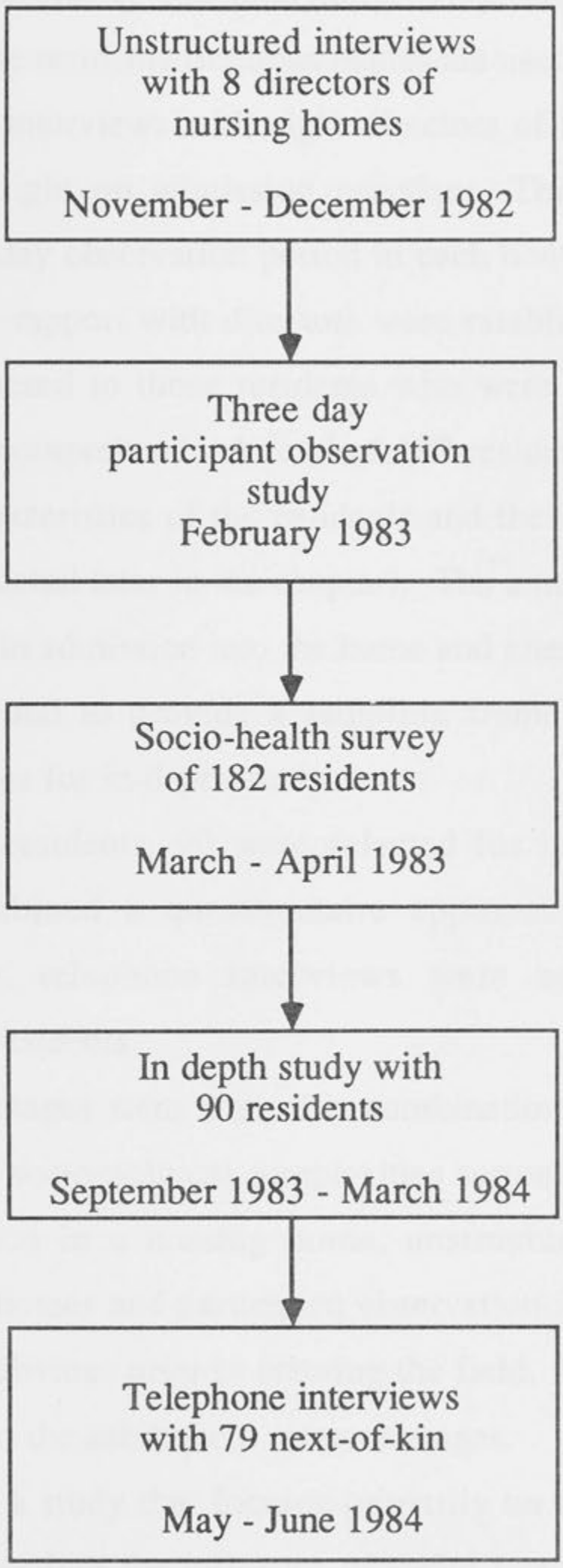
Triangulation at Work

Triangulation is 'the combination of methodologies in the study of the same phenomenon' (Denzin, 1978:291). There are several ways in which methods can be linked so that they complement and enhance understanding of the topic.

> On one end of the continuum, qualitative research can be used in an exploratory manner to help define the parameters of a problem area which is then followed by quantitative research. On the other end, we can begin with quantitative research and use qualitative research to help provide interpretation and understand the meanings that were derived from the quatitative research. Finally, in the middle of the spectrum, we can think of using the two perspectives concomitantly which results in independent but simultaneous use of quantitative and qualitative research (Ingersoll, 1983:6).

This study used concomitantly, over a period of three years, a number of research techniques: unstructured interviews, participant observation, and questionnaires (see Figure 2.1). It also includes a number of principal players in the decision to seek nursing home care; directors of nursing homes, residents and their next-of-kin. An attempt was made to also include the physician who recommended the resident's admission. However, permission to contact the physician was not given by either the majority of the directors of nursing homes or the residents. With such objections, the views of physicians were excluded from this investigation. All respondents

Figure 2.1 Variety of Data Collection Strategies



were promised confidentiality and anonymity. To protect the identity of the nursing homes and the residents fictitious names are used.

Unstructured interviews with eight directors of nursing homes were conducted to shed light on admission practices. This was immediately followed by a three day observation period in each home. Once familiarity with the setting, and rapport with directors were established, a socio-health survey was administered to those residents who were capable of hearing, communicating and comprehend. A total of 182 residents were included in the survey (the characteristics of the residents and the criteria for selection will be discussed in detail later in the chapter). The aims of the survey were to detect differences in admission into the home and interaction patterns with family and friends, and to provide a sampling frame to select a smaller number of respondents for in-depth study.

Of the 182 residents, 90 were selected for in-depth study. The in-depth study combined a questionnaire approach with unstructured interviews. Finally, telephone interviews were conducted with the next-of-kin of these residents.

Several advantages stem from this combination of methods. First, given the human and socio-political complexities surrounding the decision to place an older person in a nursing home, unstructured interviews with directors of nursing homes and participant observation identified conceptual issues that were not obvious prior to entering the field. This knowledge was then incorporated into the subsequent research stages.

Secondly, in a study that focuses primarily on the viewpoint of the older person, and examines the influence of social factors, it was important to select patients who were capable of telling their stories and likely to have

been admitted predominantly for social rather than medical reasons. A short socio-health questionnaire was administered to residents who were able to participate in the survey. This procedure identified residents who were capable of participation in a second more probing interview, and whose social situation had played an influential role in their admission.

Thirdly, because the issues surrounding the institutional decision are not well understood, the level of data needed to make a significant contribution needed to move beyond the quantitative socio-health survey. An in-depth study approach based on unstructured interviews can give a rich understanding of the meanings that the 'actions have to the actors involved and describe those meanings in culturally [and personally] appropriate terms' (Halfpenny, 1979:802). This part of the study examined the 'resident' accounts of the decision making processes. The first person understanding would have been missed if the study had relied solely on a structured format based on specifically articulated, isolated, and quantifiable variables. The quantitative design is not suited to such an analysis because the researcher is forced to design in advance the variables that affect people's experiences. In doing so, the process of interpretation from the individual actor's point of view is ignored in the process of variable analysis. Blumer states:

> The conventional procedure is to identify something which is presumed to operate on group life and treat it as an independent variable, and then select some form of group activity as the dependent variable. The independent variable is put at the beginning part of the process of interpretation and dependent variable at the terminal part of the process. The actor's interpretation of the process is ignored or, what amounts to the same thing, taken for granted as something that need not be considered (1969:133).

Analysis of predetermined variables dealing with individual interpretation dispose the researcher to ignore the process experienced by the actors under study. In contrast, qualitative research methods minimize the imposition of the researcher's own analytic device upon the respondent. This allows (but does not ensure) that the subject's own world stands in its own terms. The unstructured interviews with aged respondents revealed important elements in the decision process that could not have been anticipated in advance.

Finally, triangulation allows the researcher to examine the same phenomenon from multiple perspectives. If different methods produce largely consistent and convergent results, then the researcher's confidence in his results is increased. Findings are no longer simply seen to be a method artifact (Jick, 1979). For example, the residents' stories collected through unstructured interviews suggested that those who had not participated in the decision making process were less happy than those residents who had had some involvement. In addition, their answers to more structured questions substantiated this finding. Residents who had little or no involvement in the decision making process had a lower score on the subjective well-being scale (see chapter 5). These findings derived from different methods add support to the claim that the residents' involvement in the admission decision is an important determinant of well-being after entering the home. Where multimethods produce discrepancies in findings, recommendation of divergent results provide an opportunity for enriching the explanation (see chapter 6).

The Sample

Nursing homes and respondents were not selected to meet the criteria of representative sampling. The focus of the thesis is to identify and describe a typology of decision making situations and the role social factors are likely to play in decision making. For this reason, the criteria for selecting nursing homes and respondents centred on obtaining a range of processes likely to be influenced by the personal situations of respondents and the kinds of homes they entered. Cases were included to illustrate the widespread processes by which older people come to live in nursing homes. This sampling procedure was seen as more in keeping with the social realities of the contexts and preferrable to estimation of populations of older people who come to the nursing home from different pathways and the commonality of their situations. The sample size of 90 for the in-depth study was sufficient to ensure that the variations that existed in the admission experiences of residents had been maximised. It is in this context that the study needs to be read and evaluated.

Selection of the study population commenced when a group of directors of nursing homes from the western suburbs in Sydney attended a seminar which I presented at Westmead Hospital in 1982. They were informed about the study and their co-operation was requested. A follow-up letter and phone calls to 32 of the directors yielded 20 who were interested in participation (see Appendix A).

Of these 20 nursing homes, eight were finally selected because of likely differences in their resident population and admission policies. Whilst many homes are privately owned, there are also voluntary institutions run by charitable or religious organisations, as well as a number of government managed nursing homes. The sample covered the range of non-government

nursing homes. Of the eight homes, four are privately owned and four are in the voluntary sector. The size of the homes varied from 30 beds to 130 beds. All of the homes are located in Sydney (see chapter 6 for a detailed description of the nursing homes).

Respondents were selected to ensure that they captured a diversity of situations in terms of marital status, prior living arrangement and family support. As the following chapters will show these factors shape older people's pathways into nursing homes. A retrospective approach was chosen rather than a longitudinal design due to the prohibitive costs and complexities involved in such a design. A shortcoming of this approach is that it does not allow us to examine the possible changes in people's perceptions as they moved from their homes to the nursing homes. However, the sample does include a mix of residents who were recently admitted to the nursing home and those who had been living in the home for up to three years. This sampling allows us to monitor whether length of residency influences how people view their experiences once in a nursing home.

The Unstructured Interviews with Directors and the Participant Observation Stage

Unstructured interviews were conducted with the directors of eight nursing homes, in their own offices (see Appendix B). Information was collected on the director's views of government policies admission policies, referral networks, and the roles played by the patients, families and health professionals in the decision to seek nursing home care. The conversation was tape recorded and later transcribed. A large volume of the data on directors was collected during these interviews. Directors were later called

upon to provide additional information on a range of topics, particularly regarding the residents chosen for in-depth study. Data storage will be discussed later in this chapter.

Once the unstructured interviews were conducted, all eight directors agreed that I could spend three days in their nursing homes as a participant observer. Most of this time was spent observing directors at work, although I also used this opportunity to become acquainted with residents.

I spent most of the three days in each home sitting in the director's office and eating with staff members. I was often present when the director received a telephone call enquiring about the placement of an older person, or discussing with staff the decision to admit the applicant. Knowledge gained was later incorporated into the questionnaire design for in-depth study with residents.

This fieldwork provided further legitimation in the eyes of staff for subsequent stages of the research. Time spent talking with directors familiarizised them with the researcher and the research focus. It was important for them to understand that my purpose was not to add to current newspaper stories about bad nursing homes. At the time of my research the newspapers were running stories about the poor quality of care in nursing homes. Many directors were sensitive to these stories and weary of opening their doors to people interested in studying them. The trust established greatly enhanced data collection. Directors often gave me access to privileged information. The wealth of information collected during this stage forms the data base for chapter 6.

The trust of directors later smoothed the way for contacts with residents and family members. When I first mentioned in the unstructured interview that I was interested in talking to family members, several of the

directors expressed reservations about providing me with the necessary information to contact these subjects. After the participation observation study, all directors took on a similar role to that played by Doc in William F. Whyte's (1943) classical study, Street Corner Society. They became eager to assist me with achieving the goals of the study. All eight directors wrote letters to family members encouraging them to participate in 'this important study' and helped me to gain the cooperation of residents. However, they continued to be reluctant to write a similar letter to physicians, believing that physicians were under oath not to breach patient confidentiality. Instead of providing the names and addresss of the patient's physician, and approval to contact, I was given access to the nursing home files. This priviledge is seldom granted to researchers.[1]

Such rapport with directors would have been difficult to achieve had a standardised survey been used as it would have limited the researcher's opportunities to become acquainted with the subjects. Without the empathy established by in-depth sharing, fewer insights would have been gained. Participant observation commits the observer to define the world from the perspective of those studied and requires that he gains 'as intimate an understanding as possible about their way of perceiving life' (Shaffir et al., 1980:6). This leads to the development of a close bond between researcher and respondent. The participant observation study allowed me to develop a

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(1) When I presented a paper at an Ageing and Family Project Seminar at the Australian National University, a Commonwealth government health official was surprised that I was given access to information contained in the Nursing Home 5 Form. He informed me that it is customary for researchers to obtain the permission of the Commonwealth government before getting this access.

relationship with directors that was based on trust and respect. Equally important, the freedom to observe a director talking to a daughter about placement of her mother in a nursing home, or a resident interacting with family members, generated many ideas. These were more rigorously tested in subsequent research.

The Socio-Health Survey

As the primary goal of the study was to talk to older people about the decision to move into a nursing home it was important to select those people who were capable of telling their story. The 474 residents aged 60 and over in the eight nursing homes were approached and given the opportunity participate in the study. A person's inability to hear the questions, to comprehend them or to communicate their answers excluded them from the survey. A total of 182 residents participated in the survey. This represents 38 per cent of the resident population in the eight nursing homes, but a 91 per cent response rate among respondents who were physically and mentally capable of participating in the study. Of those eligible residents who did not participate, 11 refused to be interviewed and seven were to be discharged shortly after the study began.

The interview schedule consisted of structured, precoded questions (see Appendix C). The interviews generally lasted 40 minutes. The purpose of the interview was to collect information on the residents' socio-demographic characteristics, their health profile and social situation prior to admission.

A socio-demographic profile was obtained by asking respondents to provide information on age, prior living arrangement and marital status. Health was measured by asking residents to rate their health one week prior

to admission to the nursing home on a Likert-type five point scale. Level of disability prior to and at the time of the interview was assessed in terms of the respondent's competence to performing the Katz' index of activities of daily living. Five criteria of self-care, getting around the nursing home, dressing, eating, going to the toilet and taking a bath, were combined to form an overall measure of disability. Responses were coded as 'not requiring any help from staff', 'some assistance required from staff', or 'fully dependent on staff'.

In order to assess the resident's level of social support, they were asked to recall contact with relatives and friends during the last week prior to the interview. Information was collected on whether the contact was through a visit to the nursing home, a telephone call or letter. Residents were asked to specify the nature of their relationship with the person with whom they had been in contact, and that person's age and place of residence. Finally, data was collected on the details of the application, when the resident first moved into the nursing home, who was responsible for suggesting the move to the nursing home, and a brief account of the circumstances leading to admission.

Interviewer assessment of the respondent's ability to hear and comprehend questions, and their ability to communicate, were recorded on a three point communication scale, varying from no difficulty to much difficulty. Over three-quarters of the sample were assessed by the interviewer as exhibiting no difficulty with any of these communication areas.

Table 2.1 shows the socio-demographic characteristics of this sample. The mean age of the residents was 78 years and more than two-thirds were aged 75 and over. This is not a surprising finding given that the use of

Table 2.1 Persons interviewed in the socio-health survey and in-depth study by sex, age, marital status, living arrangement, number of days living in nursing home and health.

Patient Characteristics	Socio-health survey % (N=182)	In-depth study % (N=90)
Gender		
Male	23	26
Female	77	74
Age		
60 -74	33	28
75-84	35	39
85+	32	33
Marital Status		
Never Married	23	21
Widowed	56	60
Married	9	12
Divorced/Separated	12	7
Prior Living Arrangement		
Other Institution	44	34
Home with Others	28	28
Home Alone	28	38
Functional Health Score Upon Admission [a]		
5-8	35	40
9-11	31	60
12-15	34	-

[a] A score of 5 indicates that the resident is capable of performing all of the five activities of daily living without assistance from the nursing staff while a score of 15 indicates that the resident is dependent on the nursing staff to perform all of the activities.

nursing home increases with age. Statistics from the 1981 Australian Bureau of Statistics Handicapped Survey reveal that while three percent of those 65 years of age and over reside in nursing homes, of those between 65 and 74 years of age less than two per cent live in nursing homes. This percentage

rises to six per cent for those 75 to 84 years and more than 17 per cent for those aged 85years and over. However, it is important to remember that even among those most of risk of being placed in an institution, those aged 85 and over, the majority live in private households (Gibson and Rowland, 1984). Not only are nursing home residents largely composed of the very old, but they are also predominantly female. The great majority of residents interviewed (76 per cent) were female. This is partly explained by the greater longevity of females.

Table 2.1 also shows the marital status and prior living arrangement circumstances of the residents. Over half of the residents in the socio-health survey were widowed. The never married accounted for one-quarter of all residents. This is consistent with the results of larger national surveys which show that the widowed and never married are over-represented amongst the nursing home population (Australian Bureau of Statistics, 1982). In 1981, the residency rate per 1,000 population 65 years and over was nine for married persons, in contrast to 64 for widowed persons, 31 for divorced or separated persons and 72 for never married persons. The residency rate among never-married persons was higher at all ages for both sexes than the other marital statutes (Australian Bureau of Statistics, 1982). The higher rate of institutionalisation among the never married probably results from the lack of spouses and children, and the lower level of personal commitment from distant relatives and friends after the onset of illness.

A large number of residents were admitted from their own (or someone else's) private home. Over 56 per cent of the residents were either living alone or with someone, often with a child or spouse. For those patients admitted from another institution, 20 per cent from hospitals, 14 per

cent came from a nursing home, 10 per cent from hostels or other sheltered accommodation.

Residents had lengthy periods in nursing homes. Over three-quarters had resided in a nursing home for one year or more. The mean number of years patients lived at the nursing home was 3.5 years. At the time of admission, over a third of the residents were capable of performing most of the activities of daily living without any assistance from staff.

In comparison with the findings presented in the Australian Bureau of Statistics Survey (1982), the characteristics of the residents in this study did not differ markedly with respect to gender, marital status, prior living arrangement and length of stay in the nursing home of residents. A portrait of the 'typical' patient can be identified as female, widowed, aged over 80 and having lived in the nursing home for one to four years. However, residents in this sample were in much better health, and reported fewer mental and physical disabilities. This represents a very skewed nursing home population because the criteria used to select respondents excludes the mentally or physically disabled respondents. It is important to note that while it is amongst this shewed group of patients that one would expect social factors to loom large in the decision to seek institutional care.

In-Depth Study with a Select Sample of Residents

The purpose of the in-depth study was to gain a more comprehensive picture of the precipitating factors surrounding the decision to seek nursing home care and to examine the processes by which older people reach the doorstep of nursing homes. A questionnaire approach (see Appendix D) was combined with an unstructured format (see Appendix E). A day was spent with each respondent, with the morning allocated to completing the more

structured format and the afternoon spent chatting about topics raised by both the researcher and respondent. To ensure privacy all conversation took place in a private room without observers. The unstructured interviews were tape recorded.

The questionnaire was used to identify variable patterns while the unstructured interviews were used to generate what anthropologists call 'holistic work' or 'thick descriptions' (Jick, 1979). It is important to note here that the qualitative data were not merely 'the first step in the measurement process leading on to the construction and test of explanatory hypotheses' (Halfpenny, 1979:808). Rather they were the very core of the explanatory enterprise and were utilised to understand the meanings which residents used to 'justify' their presence in a nursing home. Theoretical themes are extracted from the qualitative data as shown in chapter 5. The qualitative data is also employed to interpret statistical relationships, and through case studies, to exemplify situations found in the quantitative data.

When selecting residents from the socio-health sample a number of considerations were taken into account. First, the sample size had to reflect the requirements of statistical analysis yet not be too large to prove cumbersome for transcribing and analyzing the mountain of data collected through qualitative methods. Secondly, residents had to be further screened on their ability to complete a more rigorous interview situation. Two criteria were used to identify eligible respondents; their scores on the communication scale and the Katz index of daily living activities. Respondents who had 'a little or much difficulty' in comprehending or communicating their responses were excluded because of the demanding nature of the in-depth study. Respondents were also excluded if they had a of score of 12 and over on the functional disability scale upon admission (see

Table 2.1, p. 33 for functional health measure). This was because these residents would have been admitted predominantly for medical rather than social reasons. The final resident sample consisted of 90 residents, which represents 19 per cent of the total number of 474 residents living in the eight homes.

Of the 90 residents, more than half were admitted directly from the community. Of these 34 were living alone, 11 living with a spouse, eight with a child and six with another relative or friend. For those residents admitted from institutions, 14 came from acute hospitals, nine from hostels, and six from another nursing home. When we examine the last address of residents who came to the nursing home from an institution, two-thirds were previously living in a private residence, usually alone or with a spouse. About a third of these residents, however, were admitted from another institution, suggesting that some residents were moving from one institutional setting to another before reaching a nursing home. The sample also displays a diversity of individual characteristics, in terms of gender, marital status and family circumstances. Table 2.1 also provides a profile of the socio-demographic characteristics of the residents in the in-depth study. The nursing home sample is predominantly female (74 per cent) and overrepresents the widowed (60 per cent) and never married (24 per cent) aged living in the community. The age range of residents was 65 to 102 years old, with 72 per cent of the sample being over 75 years old. Forty per cent of these residents required no or little assistance from the nursing staff with dressing, going to the toilet, eating, bathing or walking in the home upon admission. Given that a high proportion of the sample were physically mobile, it is not surprising that many residents perceived their health to be 'good' when they entered the nursing home. Over half of the

residents rated their health as 'good' upon admission, and 43 per cent said that they felt that their health was better than that of most people of their age. The directors' assessments of the residents' health upon admission were also favourable. Eleven per cent of the residents were assessed to be in 'excellent' health at the time of admission and 49 per cent in 'good' health. Compared with other people of the same age living in the community, directors felt that 36 per were in better health.

The questionnaire contained a number of questions on the following five areas of inquiry: (1) the aged person's ability to perform daily activity tasks prior to being institutionalised; (2) help received from family, friends and community services when living in the community; (3) the precipitating factors behind the institutionalisation decision and the issues surrounding the application; (4) feelings about living in a nursing home; and (5) social ties with family and friends since moving to the home. The structured interview centred around the development of a composite picture of the respondents' network, similar to the method used in the Ageing and the Family Project of 1050 older people living at home (Roach, 1986). It included assessment of the residents' subjective well-being and ascertained the details surrounding the application process.

A number of questions were asked to identify the persons who were members of the residents' network at the time of the interview. Information was collected about the relationship of the person to the respondent, as well as the person's socio-demographic characteristics and the kind of support offered to aged kin prior to and after admission. The residents' subjective well-being was determined by a set of questions similar to those used in the Ageing and the Family Project Survey (Roach, 1986). Finally, open ended questions concerning details of the admission process, such as the reasons for

applying, persons involved in the application process, nursing homes applied to, and basis of selection and attitudes regarding the move were asked. These questions were structured according to an instrument developed by Kraus et al (1976) to interview nursing home residents and their next-of-kin about seeking nursing home care.

In addition, conversational questions were asked to clarify answers and extract qualitative data on each of these topic areas, as well as other topics which the respondent identified as important.

Telephone Interviews with Kin

To give the study a view of the multiple actors in the decision making process, for each of the 90 residents selected for in-depth study, an attempt was made to contact a designated next-of-kin. The patient identified the most important participant involved in the decision making process to enter the nursing home. A total of 79 next-of-kin were interviewed. In eight cases, the residents had no family, and in the remaining three cases permission to contact a relative or friend was refused by the resident.

The residents' next-of-kin was sent a letter explaining the purpose of the study (see Appendix F). Because they were geographically dispersed throughout the city, and some interstate, telephone interviews were arranged.

None of the kin members who were contacted refused to be interviewed. Of the 79 next-of-kin interviews, 53 were children or spouses and the remaining 26 were siblings, nieces, nephews, grandchildren, cousins and friends. The kin sample is predominantly female (76 per cent) and between 40 and 60 years old. Thirty-four per cent were employed full-time and 16 per cent were part-time workers.

A structured questionnaire was administered (see Appendix G), with a few conversational questions included. The high cost of interstate telephone calls made it economically impossible to include more open-ended questions. Data were collected on four separate subject areas: (1) the family's involvement in the decision making process; (2) the factors leading to seeking nursing home care; (3) the details of the application; and (4) family visitation. The average telephone interview lasted approximately 25 minutes.

Coding the Data

Two separate sets of procedures were used to organise the data. The quantitative data were coded and stored on a computer in three separate files; the 182 cases in the patient file: the 90 in the patient file; and the 79 in the next-of-kin file. The 182 patient file contained a total of 96 variables with two records per case; the 90 patient file consisted of a total of 198 variables with 14 records per case; and the next-of-kin file held 37 variables with one record per case (see Minichiello, 1984). The data were coded to meet the requirements of the SPSSx package.

Coding qualitative data is much more complicated than simply reducing words into numbers or categories (Miles and Huberman, 1984). Qualitative analysis is about words and the understanding of meanings. For this reason the logic behind coding qualitative data is based on the translation of thousand of lines of words into ideas.

There were several sets of qualitative data. These were derived from unstructured interviews and participant observation study of directors, the unstructured interviews with 90 residents, and the next-of-kin's answers to

open-ended questions. The data sets were stored in the following files: (1) an original transcript file; (2) a personal log file; and (3) an analytical file.

The original transcript file contained an account of words and gestures recorded during the conversation. This generated a total of 160 pages for the director data set; 2222 pages for the in-depth resident data set; and 221 pages for the next-of-kin data set. A personal log file was maintained throughout the course of the study. This file contained impressions and details of the respondent and interview situation, diagrams of the physical setting, and ideas developed during the course of the study. Finally, the analytical file organised the data contained in the original transcipt file. As concepts and themes were developed passages from the original file were cut and placed on a separate index card under the appropriate analytical heading. Colour codes were used to facilitate combining cards on the same analytical heading from the different data sets (for a full discussion of this method of assembling and organising qualitative data see Minichiello et al., in press).

Conclusion

The decision to move into a nursing home is a highly complex and emotional issue. For this reason the research strategy used to identify and understand the issues associated with this decision included a range of diverse methods. The study included five levels of analysis and data collection: unstructured interviews with directors of nursing homes; participant observation study of directors; a survey of residents; in-depth studies with a select sample of residents and telephone interviews with the residents' families and/or friends. The views of the older person as well as those of families and directors of nursing homes were included. Although each level

illuminated different aspects of the admission process, together they yield a more complex picture of admission to nursing homes. A major strength of the study is its use of qualitative and quantitative methods. The two methodologies are treated as complementary allies rather than incompatible foes.

The study does, however, contain a number of limitations and these need to be considered when interpreting the results. First, the residents in this study are not representative of the nursing home population. The sample selected the more able members of the nursing home population; the marginal group of patients living in nursing homes. The social circumstances pulling the more disabled members into nursing homes are excluded from the analysis. Whether their experiences and circumstances are similar to those residents included in this sample can only be speculated about, although there are good reasons to think that they may be different, as one would expect the mentally disabled residents to be less involved in the decision making process.

CHAPTER 3

Journeys to the Same Stop: Stories for Entering Nursing Homes

Two competing explanations have been presented for older peoples' use nursing home care. On one hand, there is a body of medical literature that focuses attention exclusively on factors such as frailty, ill health and inability to manage the tasks of daily living (Kovar, 1977; Peter et al., 1981). This evidence is obtained by reviewing the resident's medical file or interviewing health professionals. Health related factors are emphasised because the nursing home, as a social institution, is viewed more as an adjunct to a hospital than as an old age home, and the patients' files are designed to collect medical information.

On the other hand, since the early 1970s, social scientists have been challenging the view that health factors alone can account for people's decisions to use medical services (Anderson and Newman, 1973). Studies that ask older people to explain why they use health services have found that the decision is partly determined by their social situation and the absence of informal care (Branch and Jette, 1982; McAuley and Prohaska, 1982; Wan, 1982a; Ward, 1977). These writers are critical of the medical model because it overattributes the decision to seek nursing home care to presumed physical declines associated with ageing. As Diamonds critically observes 'to read the medical file is to get to know the resident better through their sickness' (1983:279). The medical discourse that dominates the residents' portfolios obscures and omits their personal and social history. One learns almost nothing about a person's life; the years they lived prior to entering the nursing home and how this shaped the decision making process. No sociological linkage is offered to show how the person's life events and situations are

related to living in a nursing home. An emphasis on physical health draws the researcher's attention away from social explanations, such as the loss of social supports or perceptions of need.

This chapter provides a descriptive sketch of how residents and their next-of-kin talk about the decision to seek nursing home care, and presents an overview of the social processes involved in entering nursing homes. The analysis aims to be sensitive to the respondents' subjective interpretations and makes use of their own words to develop categories of processes and guide the analysis. A composite picture of the dominant and divergent themes that emerge from stories of the residents and their next-of-kin is discussed. In addition, differences in circumstances leading to residential admission are presented by living arrangement and marital status. These two factors are central to the availability of informal support (Antonucci, 1986). The aim is to uncover the reasons people give for applying to nursing homes. Subsequent chapters explore in greater detail and provide more supporting evidence on the differences between the pathways that lead residents into nursing homes. The issues surrounding the processes by which people participate in decision making and the circumstances that place them in different types of decision making situations are explored in chapters 4 and 5.

The Residents' Stories

Eligibility for nursing home care is defined by professionals and policy makers mostly in medical terms. For some residents, however, much of the need is social in origin. When the 90 residents were asked to talk about their reasons for moving into nursing homes, most concentrated on factors other than health.[1] Less than a quarter of the residents spoke about the

(1) When presenting the stories of residents and their kin the aim is to describe with words the reasons offered as important for the move. Later in the chapter, a frequency of reasons given is presented and discussed.

importance of a change in their health or a specific medical problem. If a medical condition was cited it was usually a contributing rather than determining factor. Examples included fractured femur, the crippling effects of a chronic condition, such as arthritis or diabetes, a visual impairment or 'old age'. No resident, however, was admitted without health problems recorded in their medical chart. Unlike the Nursing Home 5 Form that contained very little documentary space for the patients' social admission history, the patients' stories were rich with accounts of events that linked their admission to a specific personal history. This is not to say that references to health problems were not included in the patients' stories. With the gradual physiological changes caused by ageing, they often talked about their 'backs giving up on them' or the general loss of sensory acuity. But these were 'en passant'. Health problems for these patients, though they may have played a contributing role, were not identified as the most important factor influencing the admission decision. If health was identified as important, it was because of the dependency old age created and its influence on self-image.

Residents admitted from another health care institution spoke about being locked into an irreversible sick role. The older person saw herself as physically vulnerable, frightened that 'something much worse could happen'. 'What if I had another fall in the street and broke my legs, I'd be in a real fix then.' The older person may have tolerated a chronic condition until doctors and family members assigned medical significance to the symptoms. The family may take this opportunity to reassess the older person's ability to continue living at home. They may be anxious that more serious complications could occur if the person is living alone or with others who are unable or unwilling to provide long term support. Anticipating further physical decline, and a greater dependency on others, the older person is forced to accept the nursing home as the only alternative. People without

families may have no choice but to enter a nursing home as they have no support in the community to help them recover from their illness or accident. 'I have no children; where was I to go after they discharged me [from the hospital]?'

Other people spoke about moving into a nursing home as the result of not being able to manage with the everyday physical and emotional demands of living and fear of becoming a burden on family or friends. Over one quarter of the sample stressed that they moved out of their homes to stop the family from worrying about them. They spoke about their devoted family members providing support at great personal sacrifice. Family members were 'running themselves down' trying to maintain separate households. 'Julie's career and children' were suffering because she 'is too busy worrying about me'. Although help was generally accepted as a gesture of affection between parent and child a crisis occurred when the helper role dominated the relationship. For some, this only happened after a few months of continuous support with the cooking, house cleaning or shopping; for others, it was after many years of committed support. With the withdrawal of family support someone, usually a family member, suggested the move into a nursing home. Few aged persons had ever anticipated living in a nursing home. In their younger days, old people were cared for in the family home. Many cited examples of having helped a parent or older sibling remain at home in the past. But the modern family is perceived to be less willing to 'do the same'. They are more likely to arrange for the aged person to be cared for by professionals.

> How I came to be here? The doctor and the family all got together and they said that I could not look after myself. My grandson found this place. I did not know this place existed. They said it was difficult for me to live alone. I had problems

> carrying the shopping with my bad back. So I said, oh well, I'll go and took it in my stride (Mrs Brown, widowed, 85 years old).

People will not use services unless they perceive that there is a need. For many older people, the complaint that 'something is wrong' comes from others. For this reason, few aged persons can immediately adjust to living in a nursing home. Often, they stand outside the decision making process. It was to please their families that they moved. Having looked after their frail parents at home, many of them feel ambivalent about their childrens' different attitude towards family care of the aged.

> The only choice I had was to come here. My parents did not die in a nursing home. But I will. Things have changed. In those days, old people were naturally looked after by the family at home. There was no question of nursing homes. Today there is. They do not have the time for you. They go to work or University. And they have a different attitude. That is where the difference comes in. I don't think it is a good thing. And I am worried for young people, like yourself. What is going to happen to you when you grow old (Mrs Axon, widowed, 77 years old).

Aged persons spoke about coming to terms with living in a nursing home. Whereas they were upset and hurt by their family's decision when they entered the nursing home, after a few months they came to accept the point of views of the others. 'I knew it would not be fair if I had not come; can't ruin her life because of mine'. The change in attitude occurred, however, only after they had become 'patients'. As Tobin and Lieberman (1976) point out residents often shift their stories of why they entered the nursing home, from portraying the move as voluntary when on the waiting list, to portraying the move as coerced by family immediately after entering

the nursing home, and to finally accept their fate after having settled in the nursing home.

Some do not need others to draw attention to their frailty. Many come to believe that 'we can't manage' (Day, 1985); a story cited by one quarter of the residents. The major cues people use in deciding to seek nursing home care is the disruption of daily activities. The house has become 'too difficult to look after', the cooking and house cleaning 'too much of an effort'. The older person may find it alarming that she can no longer hold a cup of tea without spilling it in the saucer.

Perhaps frightened that a road accident could cripple them they may seldom go out. This is an attempt to stay out of trouble, but such measures can lead to depression and isolation. They are no longer the person they once knew themselves to be. Life is not going to get better. What happens '...when you stop cooking for yourself for fear that you will forget to turn off the stove, when you stop going to the shop for fear that you will fall in the street, when you stop doing the things you once enjoyed because you think you can not do them anymore?' Someone suggests moving into a nursing home because 'you are not eating properly, you are not doing anything with your life, you have stopped living.' People begin to worry 'about you'. But others do not have to remind them that they 'can't live this way'. They may delay the idea of moving into a nursing home, but as they come to accept a new image of themselves, as an old person approaching death, they see the nursing home as 'the only place that can cope with me'.

Unlike the popular belief that older people in Western societies are abandoned at the first signs of dependency, residents spoke about the attempts of children and other relatives to prevent institutionalisation. Evidence was given about family members helping them cope with their old age and assisting with the preparation of food, shopping and house repairs.

But faced with competing demands, families turned to formal agencies for relief. In many cases, this was the first statement that the family and the older person were not managing. Community services were used until a more permanent arrangement was found. Frightened of the stories that they heard about nursing homes, many waited until the family decided 'that it is time for you to go'.

A few will anticipate their dependency and make up their own mind to move. Nine of the 90 respondents mentioned 'planning ahead' as their most important reason for moving. These planners were generally people who did not have a social support network and who used nursing home care as an alternative to family support. They moved into nursing homes to escape from their loneliness and find a sense of security. They spoke of themselves as the 'lone survivors', after most of their relatives had died. They may have a cousin or nephew 'living somewhere' but the bond is too weak to ask for help: 'can't even tell you where he lives'. Referring to themselves as 'orphans', these people see the nursing home as a place that will offer them friendship and shelter. Unlike those patients who feel that they have been forced into moving by others, the planners feel fortunate 'to be here'. They entered the nursing home not to be forgotten by people, but to be with people, with the hope of being remembered. Others plan ahead to maintain their independence from their families. They see moving into a nursing homes as being loyal to their family.

> I think an old person should manage as much as she can. You should not put a lot of extra work on other people. I have said all my life, if my husband died before I did, I would never have anyone else live with me or go to live with my children (Mrs Hodges, widowed, 89 years old).

The Families' Stories

When talking about the most important reason why the older person moved into a nursing home, family members were slightly more likely than their aged relative to include health reasons in their stories. This may have facilitated their decision. Perhaps it lessened their guilt and the social stigma associated with placing a parent into a nursing home. Health factors, however, again were not the dominant themes that emerged in their accounts. Poor vision, chronic disabilities, memory difficulties, and 'old age' were seen as interfering with the older person's chances of remaining at home. Family members had difficulty distinguishing between illness and old age and singling out health as the sole reason for suggesting the move. Less than one third mentioned health problems in their stories as a contributing factor behind the institutionalisation decision.

> Yes, her arthritis forced me to think about putting her into a home but I can not say it was only that; her age had everything to do with it. And I was not available to help her live alone (Mrs Brown's son, never married, age - 50s; see p 49).

Stereotypical images of old age (Novak, 1985; Job, 1984), and policies that create structured dependency (Townsend, 1981), can place the elderly in a terminal sick role. 'She is old. She was not going to get younger'. They are seen as incompetent, unable to look after themselves. They can not be 'trusted' because they 'will forget to turn off the stove', 'take too much medication or not enough', 'not answer the door or telephone', or 'cook proper food'. Relatives used the phrase 'unable to cope' to talk about frailty, self-neglect, danger to self, and an inability to complete the tasks of daily living. The older person has become 'a constant worry', the dominant theme in the family's stories. The old person needs

continuous supervision. Anticipating that 'something will happen', the family views the aged relative through a dependency lens.

> She needs just enough help to have someone assist her with the medication, the preparation of food, shopping, and going to the shop. I did not want her to die falling down the stairs because no one would find her in time. So my sister and I often called over after work. If we rang and she did not answer the telephone, we would rush to the house. She would spend the weekends at our homes. It was safer (Mrs Aroni's daughter, married, age - 60s).

Over three-quarters of the 78 next-of-kin interviewed did not consider institutionalisation as the first solution; indeed it was only after they had exhausted family resources that nursing homes were considered. 'We were desperate; the hardest decision in our lives'. Families, like the aged persons, often postponed the decision. They found it difficult to maintain the aged person in the community. But they felt obliged to 'keep up the battle', especially if a close bond exists between them and their aged relative. Very few felt comfortable talking about nursing homes with their aged relative. Some waited until an illness forced them to raise the subject. Hospitalisation provided the opportunity to transfer the older person to a nursing home. Some had not considered a nursing home until the physician suggested it; others used the doctor to strengthen and confirm their own decision.

> I went back to see my doctor because I was heading towards a mental breakdown. I could not bring myself to putting her into a home. I had discussed the problem with the doctor and he said I had no choice. I had been thinking about it for some time, and he helped me make up my mind. He broke the news to her (Mrs Allen's daughter, married, age - 60s).

A change in living arrangement may provide another opportunity to raise the subject. Everything was fine until a parent died, family members became ill or had to move interstate.

> Once he died, she could not manage the house affairs. And since I could not have her live with me, there was only one decision to make. And she knew it (Mrs Orr's son, never married, age - 40s).

Before the nursing home solution is discussed, families generally try to maintain the aged person at home, until they can no longer cope with the physical and emotional demands of caregiving. Some will move the older person into their homes. Others think it would be a mistake to have the older person 'move in with us', especially if there is a clash of personalities. They will attempt 'to run' separate households, helping with the house cleaning, shopping, gardening, and other household errands.

A few aged persons wish to maintain their independence from their families, and rather than impose on others, refuse to accept help and make up their own minds 'to go'. The family members of planners were surprised with the older person's decision but relieved that they were not forced to make it.

> We were surprised when she told us that she was moving into a nursing home. She has always made her own decisions. And although we never raised the topic with her, we knew that she would never come to live with us. She was getting old, and my sister and I were worried about what to do with her (Mrs Carter's daughter, married, age - 50s).

Reasons cited by family members for the older person's preference to live in a nursing home were: 'she did not believe in living with her children'; 'he is a difficult person to live with and he knew it', 'she did not want to put

a strain in my relationship with my husband'; 'she could not cope with us providing personal care'; or 'he did not want to be a burden'. Other qualitative studies have shown that older people feel that the costs of families caring for them at home are too high to risk; in terms of autonomy for the aged person (Day, 1985) and preservation of good family relations (Carter, 1985).

Family members offered two very different reasons for not having the older person live with them. One explanation acknowledges that the old person may 'be in the way' of the family and risks being a nuisance. The other explanation stresses the wish on the part of the older person not to be 'a burden'. Thus, 'planning ahead', was cited as the reason for some aged persons prematurely entering nursing homes. It was the older person's decision and not that of the family. Speaking about her aunt's decision, Mrs Bennett states:

> She was not sick. It was not the doctor who told her to go into a home. She did this on her own. She was looking ahead to when she could no longer look after herself. She was answering the question, what would happen to her when she was too sick to decide what was best for her (Mrs Bennett's niece, married, age - 30s).

The family spokesperson for planners generally agreed that the decision to move into a nursing home 'was the right thing'. Mrs Taylor's sister, who is also planning to enter a nursing home, believes that people who do not have family support, should make their own decision.

> Who will look after you? You either do something about it or you do not worry about it until something happens and you are forced into a situation to think about it. We do not have a family. Both my sister and I never had any children. And

> they say that if anyone is going to look after old people, it is a daughter. Not that they always do. But we do not have a daughter and this is why we turn to the nursing home solution. I am waiting for my phone call (Mrs Taylor, widowed, age - 80s).

The most common reason given by kin for suggesting the move was 'the burden' the family experienced as a result of caring for an aged relative in the community. The older person became 'too dependent on us', and anticipating greater demands, families felt that they could not 'keep this up forever'. The burden is often described in psychological rather than physical terms. They often spoke about making family and work adjustments, changes in personal plans, competing demands on time and feelings of being completely overwhelmed.

Many said that they 'had changed' as a result of looking after an aged relative. A few reported sleep disturbance. Families with young children living at home were more likely to talk about the conflicting roles they faced when caring for both children and an aged parent. They were more likely to seek a quick exit from their caregiving obligations. Dissatisfaction and conflict with care is more likely to occur when a child or other relative rather than a spouse is the caregiver, possibly because of the inequality of exchange in the parent-child caregiving relationship (Day, 1985).

If the older person is living with the family, tension between other family members arises because someone is 'doing too much and others not enough'. The level of stress is related to whether the caregiver receives help and support from others. Siblings are 'too old' to be relied on; the children 'too busy' to share the responsibility; nieces and nephews not 'close enough to get involved'. Feeling defeated, frustrated and exhausted, the primary carer turns to a nursing home. Talking about the lack of support she was

receiving from the rest of the family when caring for her mother-in-law, Mrs Scott said:

> I could not get any assistance from the rest of the family to relieve me of constantly looking after her. The daughter and son-in-law were not willing to take any of the responsibility. They felt their marriage could not survive the strain of having her live with them. I carried the entire load and couldn't cope. This caused a lot of strain in the family and my marriage, and it got worse when I suggested she move into a nursing home. But no one else was prepared to have her live with them so why should I be the saint? (Mrs Scott's daughter-in-law, age - 50s).

In some cases, the older person's moods were upsetting the household, especially grandchildren and sons-in-laws. The only exit from such family conflict is to place the older person in a nursing home.

Family members who try to respect their elderly relative's desire for independence and provide support at a distance, face the physical strain of maintaining two households. 'Running back and forth' eventually becomes 'too much for us to handle'. Although formal services may be called upon to assume the tasks of household and personal care, the family generally retains the major responsibilities for preparing meals, shopping for food, paying the bills, checkup calls, and idiosyncratic tasks (Litwak, 1985). Formal services seldom lessened worries about 'something happening'. 'They were simply not good enough.'

> The services we could get were very limited. To begin with, the demands for them were so great that you could not rely on them all of the time. They were not enough to ease my worries. For instance, the home help service was only two hours a fortnight, and they would either do the shopping or the housework. It simply was not enough for my husband and I to get away for a few days if we

> wanted to. We couldn't rely on them (Mrs Allen's daughter, married, age - 60s; see Pp 53).

If the family bond between the aged parent and child has been weakened as a result of a divorce or family quarrel, nursing homes are the 'only alternative'. For these patients, the family exists 'in name only'. Families do not feel obligated to offer support, nor do they think the older person has any right to 'call upon us for help'.

> The divorce erased the nuclear family. My mother does not want to have anything to do with him and my sister does not care about him. This is why he is in a nursing home. I feel sorry for him but I do not care enough about him to have him live with me (Mr Jones' son, never-married, age - 40s).

Themes in People's Stories

There were many similarities in the stories told by aged persons and their next-of-kin. The stories were dominated by the theme of the older person being a burden and perceptions of not managing without the full-time presence of others. In contrast to Day's (1985) finding that aged persons living at home 'can manage', the respondents in this study of nursing home residents felt they could not manage independent living. This largely accounted for the decision by relatives or planners to seek nursing home care.

After telling their stories, residents and their next-of-kin were asked to state the most important reasons for the application. This allows comparison of similarities and differences in the factors residents and their kin members saw as important in precipitating the move to the nursing home. Table 3.1 shows that the most frequently mentioned reason given by both parties was the perception that the older person could not manage

Table 3.1 Most frequent reasons given by residents and their next-of-kin for moving to nursing home.

REASONS [a]	RESIDENTS (N=90) %	NEXT-OF-KIN (N=79) %
Older person can not manage alone	42	46
Pressure by family/ others to move	38	10
Burden on others	24	35
Health	19	25
Loneliness	16	8
Older person wants to be independent	14	15
Change in household	10	13

(a) Total of column exceeds 100 per cent because many respondents gave more than one reason

without help from others. This reason was given by 46 per cent of kin members interviewed and by 42 per cent of the residents.

As mentioned earlier, health was seldom cited as a major reason for moving to the nursing home. Less than one-quarter of residents and their next-of-kin mentioned health as a primary reason for the admission. This is not a surprising finding given that most residents selected for study were in good health and capable of performing most of the tasks of daily living upon admission. Kin members, as their stories also revealed, were slightly more likely than residents to cite health as a reason. Twenty five per cent of the kin members included health as a reason as opposed to 19 per cent of residents.

Some interesting differences do exist between residents and their next-of-kin. Kin members were more likely than the residents to mention

the burden factor of looking after an old person. Thirty-five per cent of the kin members mentioned this as a reason for the application as opposed to 24 per cent of the residents. Residents, however, were nearly four times more likely to cite the pressure placed on them by others, and twice as likely to have mentioned loneliness, as reasons for moving to the nursing home than kin members. Other reasons given by both parties were the older person's desire to maintain independence from others and a sudden change in the living arrangement of the older person.

Diversity in People's Stories

The previous pages described commonalities in people's tales of why the aged enter nursing homes. However, if we are to fully understand the factors that influence the decision to use nursing home care then we must also document the diversity in circumstance and outlook. The residents' pathway into nursing homes are coloured by their prior living arrangements[2] and family situations.[3]

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(2) Information on household composition reveals that more than half of the aged over sixty-five live with their spouse, more than one-quarter live alone and the rest live with others, although there are pronounced differences according to the person's age, gender and marital status (Rowland, 1983). For the purpose of this study it is worth noting that aged married persons, almost by definition, live with their spouse. The widowed, divorced, separated or never married aged generally live alone, although the aged widowed are more likely than the divorced or separated aged to live with children, while the never married are more likely than the other groups to be living with siblings or friends.

(3) Most elderly people are not without family ties. The Ageing and the Family Project's survey of 1050 aged people living in Sydney found that 56 per cent of the respondents had a spouse, 80 per cent had at least one sibling and 83 per cent had one or more children. Fewer than three per cent had no family members (Rowland, 1983).

Thirty-four of the 90 residents were formerly living alone.[4] These residents and their kin members offered several explanations as to why some aged people are admitted to nursing homes. Seven of them stated that their family members were unwilling or unable to offer support during a crisis or change in living arrangement. It is worth noting that five of these residents had sons but no daughters and the other two residents had daughters who were living interstate.

> I was very much on my own once my wife died. My son thought I needed protection from drinking and loneliness. I'd often went for a walk; a lonely walk really up to the pub and probably drank a little more than I should. I never thought about moving to a nursing home. My lad did that for me. He had just divorced his wife and wanted to go overseas. I suppose I had become a bit of a nuisance. He wanted his freedom and he put me in here. I think maybe he took some responsibility off his shoulders (Mr Osborne, widowed, 75 years old).

> I got shingles at the same time my daughter moved overseas. I never asked her to come home and look after me. Besides, I don't think she was prepared to give up her career and time. She is married and has a big house to look after. My brother and sister-in-law said that it was one thing when I needed my daughter torecover from the sudden death of my husband. Helen came to live with me for four years. But she was not married and living in Australia. I can't be possessive now (Mrs Axon, widowed, 77 years old; see p 49).

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(4) Excluded from this discussion are residents who were admitted from another institution. The admission circumstances for these patients are different from those residents who were admitted from the community, and these differences will be discussed in subsequent chapters. Residents who lived in another institution were admitted from the community at a younger age than residents who entered the nursing home directly from their homes. As a result their social situation (eg., marital status, social network) when living at home would have been markedly different from the middle-old to old-old residents admitted from the community. However, residents admitted from an acute hospital are included. Of the 31 residents admitted from an acute hospital, 12 were living alone and 19 were living with others.

Two of the residents could not count on informal support because of weak ties with their family. Both were men and divorced. Divorce can weaken family ties, especially for males (Mugford and Kendig, 1986). As a result when independent living becomes problematic nursing home care is the only alternative.

> Mr Owens: The wife walked out. She told me she was going to live with one of the daughters and that I had to come here. She says that I was always demanding her to do things and that I was verbally abusive. The children also told me I had to come here (separated, 81 years old).
>
> Mr Owens' daughter: It never had been a happy marriage. Dad has never been an easy person to live with and so when they separated he was left on his own. We more or less left him. He was a very strict parent. We could not bring our friends to the house or watch television after certain hours. Most of us moved out of the house at the first opportunity that came to us. Mother leaving him was his own doing. Because of our poor relationship with him, none of us were prepared to have him move in with our family. So the only other alternative was a nursing home (married, age - 50s).

Seven residents mentioned the absence of family ties as putting them at risk of institutionalisation. Five of these residents were never married while the other two residents were childless widows.

> I never married and have only a nephew. I was ill and getting old. The social worker thought it was best for me to come here. I was on my own, you see. I never knew that places like this existed until the social workers mentioned it. What choice did I have? (Miss Parker, never married, 86 years old).
>
> I married twice but never had any children. After John passed away, I got lonely and depressed. When John was alive we use to go to every function. He was a boathouse manager. Well after he died I could not go to the social functions because it was too far to walk by yourself. At first, a few of my friends would accompany me but two ladies on their own while all the other members had their husbands made me feel more lonely. So after a while I gave it up and stayed home. I had few visitors. I was not

> eating because I did not enjoy cooking for myself. I used to take too many tablets, fall asleep and not remember what I was missing in life. My sisters thought my health was suffering and they talked me into moving here (Mrs Alexander, widowed, 84 years old).

Aged persons living alone are not without informal support. Family members and friends provide both instrumental and expressive support 'at a distance' (Kendig, 1986). During the last 12 months prior to their admission, 10 of the 34 residents who lived alone received most of their help with the shopping and house cleaning from family members. All were living in their own home, widowed and receiving help from a daughter. The decision to place the aged parent in a nursing home was raised by the principal caregiver only after she had experienced great emotional and physical stress. This scenario is clearly illustrated by the statements made by Mrs Allen and Mrs Ferry and their daughters who had provided long term support to their mothers.

> Mrs Allen's daughter: My mother lived next door to us for the last eight years. She had an (eye) operation. Although I had always helped her out with the housework, when she returned home from the hospital and she had become much more dependent on me. I was constantly running to her place to do things. I had been suffering from a nervous complaint and with mother living next door I was never given the chance to fully recover. I could not carry on like this. I just knew that sooner or later I would have to make the decision or else end up in the hospital again. And it was the most difficult decision I have ever made. For a long time I fought the idea (married, age - 60s).
>
> Mrs Allen: After the operation I needed more help from my daughter. I can't see very well. And I couldn't put that responsibility on my children. They have a few problems of their own. My youngest daughter was dying of cancer, my son had a car accident and suffered spinal injury and my daughter who lived next door to me also had health problems of her own. When my daughter suggested that I move into a nursing home I thought it was a good

idea. I felt moving into the home was the best solution (widowed, 83 years old; see pp 53,58).

Mrs Ferry's daughter: Mum was fine until dad died nine years ago. Normally she could manage on her own. But ever since dad died she had a history of manic depression. When she got in one of her depressive states of mind, I would not know how I would find her. When she was depressed she would drink herself to sleep and I would have to do all of her cooking and housework. When she was not depressed she was fine. But over the years the situation became too stressful for me to handle. She was up and down all the time. I constantly was worried about her. I couldn't have her live with me. One reason is that I don't have the room. The other reason is that I could not ask my family to put up with her moods. I think if she was not so moody the lack of room would not be a problem. We could have worked out something to accommodate her (married, age - 40s).

Mrs Ferry: I lived alone for nine years after my husband died. I felt very lonely during those years. I made life difficult for myself and my poor daughter. I don't blame my daughter for putting me here. If I was in her shoes I would have done the same thing, probably sooner than she did. I was a very unhappy person (widowed, 73 years old).

Not all residents who lived alone had others suggest that they move into a nursing home. A few decided for themselves. However, depending on their family situation, different reasons were given for the decision. Four residents, all widowed and with children, spoke about not wanting to become a burden to their families, especially daughters. Nursing home care provided them with a 'way out' from becoming dependent on their families for future personal care.

> I have one daughter and two grandchildren. I have always been independent. I didn't like to think that someday I would be dependent on others, especially my daughter. I didn't want her to nurse me. I had mum for nine years and I said to my daughter I would never ask her to do that for me. That is why I decided to move here. Maybe I came here sooner than I should have, but I wanted to be in command of the situation rather than wait until it was too late and

> allow others to make the decision for me (Mrs Rose, widowed, 79 years old).
>
> A lot of old people do not like leaving their home. They believe that if they stay at home they will receive better care. They do not like the idea of going to live with a lot of other people. I find that in a place like this you get better treatment if you are sick. You are better looked after than if you are living in your own home, where you cause a lot of trouble for everyone. (Mrs Hodges, widowed, 89 years old; see p 51).

Four residents without family ties saw the move as a security against the risks of old age. Unable to rely on family support in the community, they turn to formal agencies to assist them with their needs in old age. The needs varied from protection against old age to requiring help from others with daily living assistance.

> I do not have any family. I am the last of ten children. That is what helped me decide to place my name on a waiting list. I made up my mind a long time ago. I told my husband that if I was ever left on my own I would come here and that was all there was to it (Mrs Bennett, widowed, 87 years old; see p 55).

A different set of factors were pulling residents who were living with their partners into the nursing home. Although past research shows that the most reliable source of support when one becomes ill in old age is the marital dyad (Day, 1985; Kendig, 1986), the interdependency of one spouse on another can intensify their vulnerabilities in old age. Their commitment to remain together and care for each other often means that they try to cope with their disabilities with little or no assistance from others. The marrieds are less likely to turn to family or formal support even when both partners have difficulty in performing the activities of daily living (Kendig, 1986). We often find what Johnson and Catalano (1981)

have termed 'social regression' among older married couples, who come to rely on each other to meet the demands of daily living. They hang on to independent living and postpone the alteration of living arrangements until the situation becomes 'desperate'. People formerly living with spouses are more likely than other residents to be in poorer health or require assistance from staff with daily living activities when admitted into nursing homes (Australian Bureau of Statistics, 1982).

For these reasons it becomes more difficult for their families and friends to rescue them in the event of a long term crisis. Also, providing support to one parent is easier than caring for both. The family finds it difficult to help the frail parent while also worrying about the healthier parent. To relieve some responsibilities family members suggest that the more disabled parent move to a nursing home.

Eleven residents were living with their spouse prior to their admission. They either entered the nursing home with their partner (five residents) or on their own (six residents).

Married couples fought hard to avoid or delay institutionalisation. Often this meant that one partner, usually the wife, had been playing the role of caregiver for some time and protected the other person from institutionalisation. However, a point is reached where she is unable to continue providing such support without endangering her own health or asking others to assist her with the caregiver role. The couple's independence from family members inhibits them from asking others to assume the role of caregiver. Placement of the disabled partner into a nursing home is the only alternative. Of the eleven residents who were formerly living with their spouse, three husbands were admitted because their wives could no longer provide the kind of care required to live at home. These three husbands had been receiving personal care from their

wives for more than twelve months. The decision to place a spouse in a nursing home is a difficult one, as illustrated by the following case. Mrs Haas did not move with her husband into the nursing home. Although fond of her husband, Mrs Haas saw herself as still being young and capable of living on her own.

> Mrs Haas: It was a very difficult decision for me to make and I still feel guilty about it. But I couldn't manage. I looked after him for seven months after his eye operation. He was much older than I and his health was changing quickly. It was a constant struggle to help him. I just couldn't continue to live the way I was for very much longer.
> Vic: Didn't your children help you?
> Mrs Haas: My children helped me as much as they could but they did not really understand how dependent my husband was on me. I did not discuss with them how much personal care he needed. My husband and I have always been independent. Besides they had their own families and work obligations.
> Vic: Why did you decide to place him in a nursing home?
> Mrs Haas: I never thought about it until the doctor suggested it. He told me this was a permanent crisis and that I couldn't nurse him forever. So after talking it over with my husband he agreed to move (married, 74 years old).

The death of a spouse can also precipitate institutionalisation. Three of the residents were admitted directly after the death of their partner. There are two factors operating here. Firstly, families have the perception that the surviving parent is susceptible to loneliness and unable to cope with life without the other partner. Secondly, family members are unwilling to provide the support that they think will be necessary to protect their parent from these problems. The interaction of these two factors, as illustrated by the comments made by the son of Mrs Orr, place the older person in a nursing home.

> There was really no alternative. My father passed away and something had to be done. She had been dependent on my father to manage the house just as he was dependent on her to cope with day-to-day activities. Once he died she couldn't cope. We couldn't look after her. My brother is ill and has his own family to look after. And of course, because I am a priest, I couldn't ask her to come and live with me (Mrs Orr's son, never married, age - 40s; see p 54).

Five of the residents were admitted with their partners. None of them had anticipated the move. In three cases, the person felt obligated to move when their partner could no longer be cared for at home. These residents expressed a strong commitment to their vow of 'till death do us part'. They made the decision to move with their partner because of their wish to be together and remain independent of their families.

> Looking back it was the only thing to do. My husband and I have always been very close. When he went into the hospital I moved in to be near him. We are very fond of our children and they are good children. But when I couldn't look after my husband any longer and he had to go into a nursing home I felt this was no time to be separated. So I moved with him and after he died I decided to stay. I did not want to worry my children (Mrs Rows, married, 89 years old).

Although married men also spoke about their commitment to their partners, they were more likely than married females to mention their inability to manage on their own. As other studies document (Day, 1986; Kendig, 1986) the majority of older men with a spouse have their meals cooked and house cleaned for them. Lacking the skills to perform household chores, the removal of the spouse from the house has a more disorienting effect on their lives. The comments made by Mr Hamilton provide an example of the dilemma that married men face when their wives are forced to move into a nursing home.

> Vic: When did you first think of moving into a nursing home?
> Mr Hamilton: When my wife had a stroke. I moved with her because I knew she had little time left and I wanted to spend as much of my time with her as I could.
> Vic: Was there any other reason?
> Mr Hamilton: Well I did not want my family to worry about me living on my own. I came with my wife so that they would not worry about me also. I did not like the idea of my daughter-in-law running to our place to do my cooking and stuff like that. I thought this was the best thing to do. At the nursing home all of my meals would be cooked for me and I would be near my wife (married, 85 years old).

Married men are also vulnerable to moving with their partner because they are older than their wives. Because of their age they see themselves as vulnerable to placement in a nursing home (Day, 1985). They feel it is better 'to go with the wife' than wait. Sooner or later they will 'also end up there'.

> Well I made up my own mind really. My wife had a stroke and I could not look after her nor could I live on my own. I am 93 years old. I couldn't ask my children to look after me. They and their partners work. I can not cook for myself. And I would need help with the shopping and house cleaning. That is why I decided that we should both move into a nursing home. I knew that it was only a matter of time before I also went (Mr Jukic, married, 93 years old).

In the two other cases, the couple had little to do with the decision. If it was left up to them they would have continued living at home. Without children and in the midst of a crisis, the social worker decided to admit both Mr and Mrs Wolf.

> I was living with my husband. He was much older than I. He couldn't do too much for himself. Anyways, the house burnt down and we both ended up at the hospital. They thought it would be better if we both moved to the nursing home. I suppose they were right. We were barely managing; just eating, the shopping was a problem. I was depressed

> and let the house go. We never had any children. The only relative we had was my older brother. And what could he do for us? It was not our decision to come here. They never really discussed it with us. But then what else was there for us to do. Our house was burnt down (Mrs Wolf, married, 65 years old).

Mr and Mrs Wright were jointly admitted into the nursing home because their children felt that the burden of providing support to both parents was too much for them to manage.

> Well the sons put us here. My husband had a stroke five years ago and the doctor said that he would have to go to a nursing home. And I said no I will take him home and nurse him. And that is what I did for five years with the help of the community nurse. But I was getting old myself and my sons and their wives were not willing to help me out. One day I just collapsed and the nurse found me. She called my sons. The two of them came to the house together with their wives and they said they were putting us in a nursing home. I tell you it gave me a shock. They did not want us in their house (Mrs Wright, widowed, 82 years old).

The myth that children today do not provide care to their parents has not been supported by studies on family care. Next to a spouse, children are the main caregivers (Kendig, 1986). However, as the interviews with the eight residents who had lived with a child show, there are differences in the type of support that is offered and can be expected from children. The circumstances undermining the aged parent's chances of remaining in their children's household are complex and hardly ever involve a single explanation. The ability to care for parents is partly dependent upon the children's gender, their affectionate feelings towards their parent, their expectations about what is reasonable support to offer and other competing obligations.

Since women have traditionally been assigned the care-giving role, gender is an important factor in the availability of care. Residents who were

living with a son spoke about the limitation of support they could expect to receive from their child or daughter-in-laws.

> I had an eye operation and went to live with my son and his wife for three months. I have two wonderful sons but I was not prepared to put myself onto them for very long so that their wives would look after me. Maybe if I had a daughter I would have stayed with her for much longer (Mrs Foreman, widowed, 89 years old).

Interestingly enough, all but one of these residents had lived with their sons for more than twelve months. Mrs Rees had been living in her house with her unmarried son for the last 10 years. Until very recently she was responsible for doing most of the cooking and housekeeping. With the onset of her illness, she was no longer capable of performing these tasks without help. Unable to assume these household responsibilities and care for his mother, Mrs Rees' son placed his mother into a nursing home.

> Mrs Rees: I was living with my son. I did all of his washing, ironing and cooking. I never returned home after a short stay in the hospital because my son could not look after me. To begin with he worked. And I couldn't expect him to do the housework and feed me. I was the one who was looking after him (widowed, age - 80s).
>
> Mrs Rees' son: Although I lived with mother I was seldom home. I often went interstate because of my work. With the stroke, which left mother without the use of her right arm, what was I to do. I couldn't stay home and look after her. So I discussed it with her that she move into a nursing home. She knew that this was the only thing to do. When I mentioned it to her she said 'I understand' (never married, age - 50s).

In those cases where residents were living with a daughter a different picture emerges. Often the flow of help was from daughter to mother, and these residents had lived with their daughters for a much longer time. The bond between mother-daughter is stronger than between father-daughter or

between father-son (Gibson and Mugford, 1986; Job, 1984; West and Simmons, 1983). Neither the commitment to provide support or close emotional bond, however, was enough to postpone further the decision to seek nursing home care. For some a sudden change in the health of the parent brought the caregiving relationship to a crisis. Like many elderly people, children re-evaluate their options when a crisis emerges.

> Mother lived with me for the last three years. I did not mind this arrangement because generally speaking she was looking after herself. I was working and enjoyed coming home to her. However, she was feeling lonely and demanding more and more of my attention. My brother and his wife live outside of Sydney. And mother is not a very sociable person. I decided to put her in a home. As she probably told you she was not happy with my decision (Mrs Young's daughter, separated, age - 40s).

In other cases, the parent's frailty becomes more apparent over the years. Unable to cope with the constant worry that something 'horrible was going to happen', the family turns to nursing home care.

> It all boils down that I could not cope with her frailty. Mother had lived with me for the last eight years. She is a very sweet lady and my sister and I love her very much. But she was getting on in years, she was 89 when she moved to the nursing home. I was worried leaving her alone. I would be thinking she is going to die in the bathtub and I would find her. Such horrible images were running through my mind. I couldn't cope with them. It reached the stage where I would not leave her for a minute. So the family decided to place her in a home. Everything has turned out for the best. Mother understood our concern and agreed to the move (Mrs Greene's daughter, married, age - 50s).

Children do express filial responsibility towards their parents. This is why their initial response to a crisis is not to place their parent in a nursing home but to provide home care.

Some residents had temporarily moved to their children's home prior to their admission. Children saw this arrangement as 'buying time' until something else could be 'worked out'. Often there was disagreement between family members on what was the next course of action. Husbands were complaining to their wives that their mother-in-law could not live with them forever, the eldest daughter to the rest of the family (usually sisters or sister-in-laws) that they were not doing their share and daughter-in-law's to their husbands that they would not live with their mother-in-law.

> I carried the entire load. My husband was not helping me as much as I wanted him to. And this was his own mother. This caused a lot of tension in our marriage and we eventually split up. So I arranged to move her to the nursing home (Mrs Scott's daughter-in-law, separated, age - 50s; see p 57).

Along with family objections, there were many other factors that prevented children from having their parents move with them permanently. The children's employment or other family obligations put restrictions on how long they were prepared to provide such support.

> I am an airline pilot and spent a lot of time away from home. I really could not ask my wife to look after my mother. She did not require much help but my wife felt uneasy leaving her alone in the house (Mrs Usher's son, married, age -40s).

> I asked mum to move in with me because I thought she was lonely. I didn't think it would be so complicated. She was constantly telling my children how to live their lives. And she began to interfere with my life. I had to ask her to go because we were constantly fighting (Mrs Thompson's daughter, married, age - 40s).

The provision of support is very much coloured by the history of the parent-child relationship. If the bond between a child and parent is weak it will not be long before children reevaluate their filial responsibilities.

Mrs Yates: I only have one son and we have never really been all that close. When my husband died I felt lonely and started to drink. My son asked me to go and live with him and his family. It was the biggest mistake I ever made. My daughter-in-law and I have never been friends. Billy went off to work and his wife would drive me mad. The tension in the house was such that you could cut it with a knife. My son put me in here. He never told me about it. I feel like an old dog who has been dumped (widowed, 68 years old).

Mrs Yates's son: I have never felt close to my mother but I felt sorry for her. She was constantly drinking and one day she attempted to kill herself. I found her in her flat with an empty bottle of pills next to her. Although my wife was reluctant we asked her to move in with us. But she is a difficult women; her own worst enemy. She was creating so much trouble in the house that I had to put her in here. I think it was a mistake to ask her to move with us. Since then we rarely see one another (married, age - 30s).

Despite the importance of the conjugal family, living with distant relatives or friends is far from uncommon in Australian households. In Sydney, 12 per cent of the aged are living with distant kin or friends. The never married are more likely to form a household with friends, siblings or nieces and nephews than married, divorced or widowed aged persons (Rowland, 1983).

Six of the residents were living with friends or distant kin members. They were receiving different kinds of support and care than age persons living with a spouse or child. This is partly due to people's expectations about entitlement. All were doing their 'share' of the cooking, shopping and housework. If they were living with friends of the same age they did not expect the other person to rescue them from institutionalisation in the event of a crisis. Joint living is based on the mutual exchange of support and affectionate ties rather than the provision of long term personal care. As illustrated by Miss Kaye the collapse of the household can have a direct

consequence for the other, especially when there are no other kin members or friends to call upon for support. Miss Kaye had been living with friends of 'the same age', and when they decided to move into a nursing home, so did she.

> I was living with these friends, a husband and wife. They had no family, like myself. They were getting on and they decided to move into a nursing home. They sold their house. I had no where to go and I was not getting younger. So I also decided to move with them. Father James told us about this place. I never thought about it until they raised the issue. I probably would have still been living at home had it not been for my friends moving (Miss Kaye, never married, 84 years old).

Another four residents were living with a niece, sister, or granddaughter. Their admission was the result of the older person demanding more care than their household members were willing to provide. Distant relatives have a lower care threshold than spouses or children (Kendig, 1986). Often other obligations, such as caring for their own parent or young children, leads to the withdrawal of family support.

> My aunt was living with us and everything was fine until she broke her hip. I also had my mother living with us and I couldn't look after both of them. I saw no other alternative. So I suggested that she move into a home (Mrs Keen's niece, married, age - 40s).

More distant kin are also more likely than a spouse or child to express reservation and ambivalence in assuming the role of caregiver. The combination of such feelings and other responsibilities means that they will turn to institutional care when the chance presents itself.

> I did not mind grandma living with us except that I started working part-time at the same time she fractured her hip. She required care and I was not prepared to give up my work. I also have two young children and they demand a lot of attention. Also I was receiving very little support from my

> father and brother. This did not worry me as much as it upset my husband. So I thought her accident was a good time to suggest she go into a home. She was not happy with the idea but I had made up my mind. I had my husband, children and myself to think about (Mrs Renzi's granddaughter, married, age - 30s).

Conclusion

A number of common themes run through the stories of both the residents and their kin. Many residents saw themselves as not being able to manage without the help of their families and felt that the decision to move was often made by others. Kin members spoke about the dilemma between wanting to care for their aged relatives or friends at home and the burden of providing that support. However, differences do exit between residents, and these may be influenced by gender, marital status and prior living arrangement circumstances affecting the decision making process.

The findings raise a number of important issues about how people make decisions to use nursing home care. These are: how do family members and health professionals exclude older persons from the decision making process, and what are the consequences of such actions; and are there differences in how residents reach the doorsteps of nursing homes? Chapters 4 to 6 will address these questions.

CHAPTER 4

Someone's Decision : 'That is How I Got Here'

One of the major themes that emerges from the previous chapter is that the decision to enter a nursing home is seldom made by the older person. If the elderly are not responsible for the institutionalisation decision then who are the decision makers? To address this question, residents were asked to nominate the person who first suggested that they move into a nursing home, to identify other people who helped make the decision, and then select the person who was most involved in the decision to obtain nursing home care. This approach captures the diversity in the players involved and offers a better understanding of the negotiations that take place between the older person, family, health professionals and directors of nursing homes.

Several key issues associated with the decision making process will be addressed. First, the chapter will identify who the decision makers are and the role they play in seeking nursing home care. Second, as different people may be involved, the factors that influence who is selected to make the decision will also be discussed. To highlight how the residents' social circumstances affects the selection process of players involved in the decision making process, case studies from different types of living arrangements prior to the move to the nursing home will be presented. Living arrangement may affect how people perceive their situations, the options available to them and who may become involved in the decision making process. The case studies are selected not because they are statistically representative of the circumstances of residents in a given category but

because they illuminate the factors that determined which person will be called upon to make the decision.

The Decision-Makers

Who are the decision-makers? As shown in Table 4.1, people play different roles in the decision making process. The individual who first raised the topic of nursing homes with the older person is not always the most influential actor in the decision making process. Although residents recalled the general practitioner as the person who often 'broke the news', they saw family members as the most important participants in the decision.

Table 4.1 : Person who first suggested and was most involved in the decision making process.

Relationship to Patient	First Suggested	Most Involved
Self	6	18
Family members/friend	11	42
Physician	59	23
Social worker/nurse	14	7
Total	90	90

Whereas 11 patients named family members, usually a daughter or son, as the person who first raised the subject of moving into a nursing home, a family member was about four times more likely to be named as the person most involved in making the decision. The family is providing some sort of support but finds the caregiving role too burdensome. The demands

of continuous care disrupts their lives. As we saw in the previous chapter, family members view the older person through a 'dependency lens'. They see their aged relative as not coping with independent living. It is this perception that places the elderly in a terminal sick role. 'She is old. She was not going to get younger'. The older person becomes a constant worry to the family. The family creates a character portfolio that emphasizes the dependent nature of their aged relative. Once this is done they turn to institutional care.

Very few family members, however, find it easy to raise the topic of nursing homes. To suggest that a parent enters 'such a place' generates a feeling of anxiety, and perhaps indicates to others that the family has abandoned or dumped the older person. For these reasons, family members spoke about institutionalisation as the 'last solution'. Indeed, it was only after they had exhausted personal resources that nursing homes were considered. 'We were desperate; the hardest decision in our lives'. Often the responsibility of assisting the older person with independent living fell in the hands of a few individuals, usually a wife or daughter. Over the years, the principal caregiver felt that she could no longer cope with the physical and emotional demands of 'looking after mum'. Not feeling confident about the effectiveness of community services, nor being able to transfer the responsibility to other family members, the principal carers call for a re-evaluation of the situation. Thus, the early history of the decision making process will involve some kind of discussion with family members other than the aged person. In many cases, the older person is the last person to be consulted.

Family discussions are held not only for the sake of reaching a unanimous decision but also to alleviate the guilt feelings associated with

failing to maintain the older person at home. The case of no other alternative is presented. This makes the family's argument so much more convincing when confronting the older person about moving.

> Mrs Earl's daughter-in-law: We had a family discussion.
> Vic: Who is the family?
> Mrs Earl's daughter-in-law: The two sons and the wives. She had developed sugar diabetes. She was living alone and not looking after herself. We all agreed that none of us could look after her. It would have been too difficult for her to come and live with us because she is a difficult person to get along with. So we thought that putting her in a home was the best thing to do (married, age - 50s).

> My sister and I had mother living with us for the last eight years. We took turns. But I was worried of leaving her alone after her accident (Mrs Greene fell and broke her arm when the family was out one night). My sister and I and our husbands got together and we discussed what we would do with her. It was my husband who first raised that we place her in a nursing home. At first, my sister and I did not like the idea. We both cried because we felt that if this was what it had come to then we had failed as daughters. But we also knew that she was getting older and we could not keep up the pace of looking after her. So we all agreed we would put her into a home and see if it would work out. And it has (Mrs Greene's daughter, married, age - 50s; see p 72).

Once family members agree that the older person needs nursing home care, a medical diagnosis from a 'scientific' source is sought to legitimate the entire decision making process.

> The doctor made it easier for us. It was he who suggested to her that she move into the home. She asked about community services but he told her that in his opinion he did not think she was capable of looking after herself. She told her that it was best if she was receiving constant care in a home (Mrs Earl's daughter-in-law, married, age 50s).

The aged person is often unaware of the discussions between family members and health professionals and only after admission do they 'put the pieces together'. Their participation in the decision making process is usually as a third person in a kind of collusion between family, health professionals and directors of nursing homes.

> My family and doctor thought I had to come here. I wasn't asked. I didn't even know they (her two sons) were thinking about it until the doctor told me (Mrs Earl, widowed, 70 years old; see p 80).

As chapter 6 will discuss, family members will often have arranged the interview with the director of the nursing home and the doctor. The director and doctor's first observation of the older person is gathered through the words already chosen by the family (Clough, 1981; Diamonds, 1983). He records the incriminating evidence about how the family worries 'about mother', her increased forgetfulness, her failure to identify people or remember special occasions, the untidy room, the turned on taps and the resulting emotional strain all this imposes on the family. Often this information is recorded prior to examining the patient. Under pressure from the family to act quickly and decisively, it is inevitable that the physician's decision is partly influenced by the needs of his informants. This establishes the family as the responsible party to whom information can be divulged, while identifying the aged person as the silent patient (Goffman, 1961).

Goffman notes that the patient often feels betrayed by her family as a result of the three-party situation.

> ...upon arrival at the office the prepatient finds that (she) and (her) next-of-relation have not been accorded the same roles, and apparently that prior understanding with the next-of-relation has been put

> in operation against (her). The professional sees the prepatient alone, in the role of examiner and diagnostician, and then sees the next-of-relation alone, in the role of advisor, while carefully avoiding talking things over seriously with them both together (1961: 137-38).

The family may have already made up their minds to institutionalise their aged relative prior to the consultation. They may be looking for a physician who will support their decision and 'break the news'.

Residents recognised that some form of collaboration exists between the family and physicians. As can be seen in Table 4.1, while 59 residents said that the doctor first mentioned that they should move into a nursing home, when they were asked to select the person who was most involved in making the decision for them, only 23 residents nominated physicians. For those aged persons admitted from the community, the doctor acts primarily as the family's agent. His role is to assist the family in persuading the elderly person to seek nursing home care. The physician is the architect who is responsible for placing the person into a sick role (Parsons, 1951). He may give the patient 'a moral judgement talk' about how much of a burden she has become to others. The physician uses the family's testimonial account to justify the admission. By placing the older person into a nursing home, he is 'curing' the needs of his other patient - the family.

> The doctor explained how I was worrying them. We had a little chat and he said it would be more sensible to move into a home because the girls would know I'd be well; there would always be somebody here (Mrs Greene, widowed, 92 years old; see pp 72,80).

> My granddaughter got the doctor to talk to me. And he said I was not being fair to Margaret, who was working part-time and had two children to raise. He said, 'how was she going to cope with you in the

> house. What was she to do when she went to work during the day? She would have nervous breakdown worrying about you!' So I just said I would come if he really thought it was the best thing to do (Mrs Renzi's granddaughter, married, age - 30s; see p 75).

Patients who had others make the decision for them mentioned the burden story to justify their entrance into nursing homes. Perhaps having heard it first through their doctor, and then repeated by their family, they come to accept this explanation.

> Why did I come here? Because my doctor told me that I had reached a certain stage and that I would be less trouble to my family (Mrs Gardner, widowed, 84 years old).

Nurses and social workers providing home help can alert the older person and her family to some other possibilities for care arrangements. Perhaps they are anticipating a decline in health or the inability of community support to maintain the person at home. While nurses and social workers may raise the subject of a nursing home, and arrange appointments with doctors and nursing home administrators, they are seldom mentioned as the person who 'had much say' in the final decision. Social workers are less likely than doctors to suggest admission or to have their recommendation accepted by the older person. Their involvement is in planning the admission. Only seven residents identified a social worker or nurse as the person who was responsible for their admission. These respondents had no family members to assist them in making the decision to enter a nursing home. They were in an emergency situation, often living alone or in another institution, and a decision had to be made on their behalf. There was very little consultation with the patient. Once a bed was

located, most people were moved to a nursing home of which they had seldom heard, nor visited. For the 90 in the sample, only 28 residents had visited the nursing home prior to their admission.

As the stories of residents and kin illustrate aged persons seldom think about living in a nursing home. Admission to a home is something that happens to others. After all, many helped look after their parents at home. Very few placed their aged parents in a nursing home. They may prefer not to live with their children but they do expect to receive support from a distance from their families (Kendig and Rowland, 1983). It is not surprising that only seven per cent of the residents said that they first raised the topic of nursing homes with their family. But when others raised the topic and gave advice, a much larger number of them (18) said that 'after listening to everyone else, it was my decision'. Such persons did not want to become a burden to others, or they have no family support available to them. They sought the advice of doctors, social workers or family members to help them with the administrative details of entering a nursing home.

Living Arrangements and Participation in the Decision Making Process

Participants in the decision making process depends on the older person's living arrangement and social network. One way to analyse the decision making process is in terms of a cast of actors. Each scene, represented by the person's prior living arrangement, has a different cast of participants, decision making activities and dilemmas.

A person's living arrangement ultimately interacts with other factors, such as marital status, to produce different pathways into nursing homes. The type of living arrangement colours the care options that are available. For instance, Kendig (1986) found that whether an older person lived alone,

with a spouse, or with family members was more influential in determining the kinds of support received than were levels of physical disability. Table 4.2 shows how different people will be involved in the decision to seek nursing home care in different living arrangement. There is a significant relationship between the resident's prior living arrangement and their preceptions of who the person most involved in the decision making process ($\chi^2 = 49.56$, $p < .01$).

Table 4.2 : Person most involved in decision making process by patient's prior living arrangement

Relationship to Patient	Prior Living Arrangement		
	Another[a] Institution %	Living with Others %	Living Alone %
Self	10	20	38
Family members/Friend	6	72	44
Professional	84	8	18
Total	100%	100%	100%
	(31)	(25)	(34)

[a]This includes residents who were formerly living in another nursing home, hostel or long term care facility. They are included in the analysis because this group sheds important light on the decision making situation of people who find themselves already in an institutional environment.

Patients who were living alone, with others or in an institution differ with regard to the role played by physicians, social workers and nurses.

More health professionals are involved in the decision to obtain nursing home care when the resident had been living in another nursing

home, hostel or long term care facility. Those admitted from another institution were ten times more likely than those who lived with others, and five times more likely than those who lived alone, to identify a health professional as the key decision maker.

Residents Transferred from Another Institution

A number of patients are transferred to the nursing home from hospitals, hostels or other nursing homes (Howe, 1983). Over one third of all admissions into nursing homes are from another institution (Commonwealth Department of Community Services, 1986). A change in the patient's health, termination of medical treatment or the need for more extensive or long term care can be reasons for discharging the person to a nursing home. Health professionals exert considerable influence in arranging the admission. Even though some form of discharge planning is usually available, the administrative pressures to transfer patients to a long term bed forces health professionals, such as social workers and physicians, to make quick decisions. The older person is frequently the last person to find out about the move. Of the 31 residents who were admitted from another institution, 25 felt that they had 'little or no say'. As is illustrated by the case below, Mr Rand, a resident admitted from a psychiatric hospital, people who have no family support and formerly were living in another institution, were particularly vulnerable to being excluded from the decision making process. Health professionals often see no other alternatives but to transfer these patients into a nursing home.

Mr Rand

Mr Rand is 79 years old. He never married and lived most of his life 'on the farm' with his parents and siblings. He had a nervous breakdown and was admitted to the 'mental' institution in 1940. 'They call it the psychiatric hospital these days', he said, to remind us of his long term association with the hospital.

He traces the origin of his depression to financial troubles. With his father in hospital, Mr Rand, the eldest son, was responsible for managing the family's business. But things did not go well.

> The dairy farm was in trouble. We had a bank loan to pay. And we also struck bad weather conditions. 1939 had been an extremely dry year. We hardly received any rain. The dams were dry. And I got run down, went funny.

He was the victim of history; at least that is how he explains his 'bad luck'. He 'got ill' at the wrong time. There was a depression and war. Under normal circumstances, society would have cared for him 'in a different way'.

> They were probably just as distressed as I was; it might have been more than distress. Everyone was discouraged. And they did not have the patience to understand my situation. The doctor did what was best for the family. He summed it up and said 'you can't stay here and trouble others'. And off I went.

There were few community services to help the family maintain the frail and ill at home. People were self-reliant. Besides, they had 'more important things to worry about. The war. Surviving.'

Mr Rand lived at the psychiatric hospital until he was transferred to the nursing home. He lived in the psychiatric hospital for over 30 years!

His medical file shows that upon admission he suffered from chronic schizophrenia. At the time of interview, however, Mr Rand was able to dress, bathe, eat, go to the toilet and leave the nursing home without any assistance from the nursing home staff. He does not use any mechanical aides nor does he have a bowel or bladder disorder. The senior nurse described his overall physical health as 'excellent', and remarks that there has been an overall improvement in his mental condition. He is no longer dependent on medication to control his moods and depression. Although Mr Rand has a unique personal history, he shares much in common with people who were long term residents of other institutions. Over the years they have become dependent on institutional care. This dependency prevents many from being discharged back into the community. Talking about why Mr Rand was not discharged home, the senior nurse explained that 'he has lost the ability to cope with ordinary life, like paying bills, going shopping'. In addition many long term patients have neither a home nor family to which to return. Out of a family of 8 children, Mr Rand and his sister are the only survivors. Mr Rand's sister is old herself. If she was unwilling to care for him when Mr Rand was younger, it is unlikely that she would look 'after me now that I am old'. He resents his sister for abandoning him in an institution.

Not having a say in the decision to move to the nursing home is something else that Mr Rand shares with the other residents. He was not consulted nor was his sister. The hospital authorities decided 'for us'. Mr Rand would have preferred to remain in the psychiatric hospital. It took him 'a long time' to adjust to living in a mental institution. He was afraid that he would not adjust to living in a nursing home. He did not know what

to expect. That frightened him. But he was accustomed to placing his faith in the hands of others. As he reasoned, what choice did he have.

> I could not say 'no, I do not want to go'. They give the orders, don't they? And as a patient, I would have to follow them.

The social worker informed him that the nursing home had better facilities to care for old people. And he was an old man.

He has no future plans. And no, he does not expect to leave the home. 'I never bother with such thoughts'. He has yet to spend a night out of the hospital or nursing home. 'I certainly will not change my way'. Where is he to go? His sister seldom visits. 'Places like this', he believes, separate a person from his family and the rest of the world. Mr Rand knows his predicament only to well, and he came to terms with this a long time before he was admitted to the home. He only has one home; and this is it.

But not all of the residents admitted from an institution were without family ties. Residents admitted from a hospital often required convalescent care. The physician or social worker may discharge the patient to a nursing home until the family comes to terms with the crisis and decides on what to do with their aged relative. In the midst of a crisis, there may be no option but to follow the advice offered by health practitioners. For some families, as is illustrated in the case below, Mrs Renzi, the crisis provided them with the opportunity to place their aged relative in a nursing home without taking direct responsibility for the decision. The family turns convalescent care into permanent care, especially when care is coming from more distant relatives, such as nieces and grandchildren (Cantor, 1980).

Mrs Renzi

Mrs Renzi is 83 years old (see pp 75,83 for earlier discussion of case). When her husband died three years ago, she went to live with her granddaughter, Christine. Mrs Renzi has one son. But they seldom see each other because Mrs Renzi and her daughter-in-law 'do not get along'.

Whilst living with her granddaughter, Mrs Renzi 'did her share in the house'. She cleaned her own room, cooked and occasionally helped with the general housework. She often babysat her two young great grandchildren. When Christine started working part-time, Mrs Renzi joined the senior citizens club so that her granddaughter 'would not worry about me being alone in the house'.

Living with her granddaughter was 'working out' until she fell in the house and fractured her leg. She was hospitalised for six weeks. At the end of her treatment the social worker suggested to Christine that she admit her grandmother into a nursing home. Christine had never thought about placing her grandmother in a home. But things had changed. The accident reminded Christine that her grandmother was old. The accident left Mrs Renzi dependent on others. When she was discharged from the hospital, Mrs Renzi required someone to help her with walking, dressing, going to the toilet and shower. Christine did not mind having her grandmother living with her as long as it did not interfere 'too much with my life'. Unable and unwilling to provide home care to her grandmother, Christine decided to act on the social worker's recommendation and place her grandmother in a nursing home.

Mrs Renzi had little say in the decision. She was transferred from one 'hospital to another'. When her granddaughter first raised the subject, she cried and objected to the move. 'I told her I would not go'. With the

help of the doctor and social worker, Christine was able to persuade Mrs Renzi to move to the nursing home.

Mrs Renzi's health has improved since she moved to the nursing home six months ago. She requires no help from the staff. However, her granddaughter has decided that Mrs Renzi should continue to live in the nursing home. She has young children to look after. And Christine's husband resents his father-in-law for not looking after his own mother. During her absence they enjoyed the freedom of not having 'another person in the house'. However, Christine's decision has placed a strain on her relationship with her grandmother. Whenever her granddaughter visits, Mrs Renzi complains about living in a nursing home. She has asked Christine 'a million times' to take her home. Christine does not visit as often 'as I should'.

Living with Others

Table 4.2 shows that aged persons living with others run a higher risk of having a decision made for them by family members or friends. While 72 per cent of residents living with others mentioned a family member or friend as the person who made the decision, only six and 44 per cent respectively of those admitted from another institution or living alone saw a family member or friend as the key player behind the institutionalisation decision. Perhaps this is the cost older people have to pay when they decide to live with their families. In return for losing their privacy and altering their life styles, family members feel that they have a right to determine the fate of the older person. Under closer scrutiny, the family may find signs of disability that requires long term care, which could

have been kept 'backstage' (Goffman, 1971) if the aged person was living in a separate household.

The elderly are not abandoned at the first signs of dependency. Family members often move the older person into their homes to avoid institutionalisation (Tobin and Kulys, 1980). Family care is not without considerable personal and financial costs to the caregivers (Australian Department of Social Security, 1982). As family members deplete their ability to maintain the aged relative in their homes, nursing home care becomes the other alternative. The principal caregiver may be under pressure from a spouse or child to seek nursing home care, as is illustrated in the following story told by a daughter, whose 90 year old mother had been living with the family for eight years.

Mrs Greene

Mrs Greene is 92 years old and when her sister died, her two daughters were worried about 'leaving mum alone' (see pp 72,80,82). They decided to 'take turns in having her live with us'. As their older children had left the family home, they had 'plenty of space'. 'Everything was fine', until Mrs Greene's health 'began to fail'. She was no longer mobile. Mrs Greene often needed help 'to do little things in life'.

Prior to moving into the nursing home, Mrs Greene was living with her eldest daughter, Pat, and had been alternating between the daughters' homes for the previous eight years. Afraid of leaving her mother alone, Pat seldom left the house. Mother had become 'a constant worry'. She was afraid she would discover that 'mother had died in the bathtub 'and that she 'would find her'. Obsessed with such thoughts, Pat was constantly 'fussing over' her mother's welfare. 'I was frightened how I would find her each

morning'. She often 'checked mum's room' in the middle of the night. Pat's health was affected by her 'mothering' of Mrs Greene. She seldom slept at night and was easily agitated.

Her moods were upsetting the rest of the family. Her husband had just retired and was looking forward to enjoying life with his wife. Instead, he found her to be 'tied up with mother'. Although Mrs Greene 'cleaned her own room', Pat spent a 'lot of time' taking 'mother to the doctor', helping her with the medication and preparing 'special meals'.

But most troublesome to him 'was that she fussed over her'. His wife had 'given up' their social life. Each time they went out, she had to arrange for someone 'to look after mother'. Only when a 'babysitter' was found would Pat leave the house.

Fighting for his wife's attention, Pat's husband decided that 'something else had to be arranged'. He had discussed his frustrations with Pat's sister and she was also concerned about the situation. A family meeting was called and the question of putting Mrs Greene in a nursing home was raised. It was not an easy decision; many tears and emotions were displayed. They all love Mrs Greene, but the family was not coping. They felt guilty about suggesting to their mother that she move into a home. Had they failed as a family? Why were other families able to manage and not them? Were they too concerned about what could happen to Mrs Greene? Maybe it was their attitude that was creating the problem, Pat argued. No, the family replied, they had done 'all we could'. She was getting older and so were they. They agreed that 'it was the best thing to do'. The only problem was how 'to break the news to mum'. They decided to 'scout for a place' and once they 'found a home we thought she would enjoy living in', they would show it to her. They also arranged for the doctor to have 'a chat with her'.

All of the arrangements were made by her two daughters. Mrs Greene did not choose the nursing home. 'No they chose it for me'. She was not upset about her family's decision. She knew that her children 'were acting out of concern for me'. Besides, she felt 'that things had got out of hand. They would not let me go to the toilet on my own; that is no good, is it?'

Living Alone

A more complex mix of support is found amongst those who live alone, especially for those without family ties. They are more likely to use community services and to contemplate using institutional care (Kendig, 1986). Although Table 4.2 illustrates that people who were living alone still saw family members as the key decision makers, they were more likely than those who lived with others to have made their own decision to move into a nursing home. Whereas 38 per cent of those living alone nominated themselves as the person most involved in the decision, only 20 per cent of those who lived with others mentioned themselves in this central role. As the following chapter will discuss only a few of the residents decided for themselves to move into a nursing home. Day (1985) has called these people planners, and as the case below highlights, one of the main characteristics of planners is their sense of independence from others. This is reflected in their desire to live alone and not become a burden to others.

Mrs Carter

Mrs Carter is 84 years old and has been widowed for the last six years (see p 54). When her husband died her three children suggested that she move in with them. Instead, she decided to live in her own home and

receive support from a distance from her children. They would 'drive her places' and occasionally 'did the odd things around the house'. Mrs Carter was 'healthy' and 'did things myself'. When she moved to the nursing home two years ago, she was able to bathe, dress, go to the toilet, and walk without any difficulty or assistance.

It was her decision to move into a nursing home. 'I suggested it to myself'. Unexpectedly, she announced to her family that she was going to move 'into one of those homes'. 'She never mentioned it before then', explained her daughter. Mrs Carter is a person 'who makes her own decisions'. Her children were not asked to participate. 'It would not have mattered what we thought'. It was a surprise to the family that she had made enquiries about moving into a nursing home.

But for Mrs Carter this was not a sudden decision. She had been anticipating the move since her husband's death and for the past year, she was gauging 'when my time had arrived'. Her children had their own families. 'My daughter has four boys to rear and she did not have the space, my eldest son also has a large family and the other daughter lives in Western Australia'. Equally important, she was not prepared to change her habits because of someone else's 'house rules'. She portrays herself as an independent person; she would not permit her children to see her 'any other way'.

And why postpone 'the inevitable outcome?' Mrs Carter was not prepared to wait until she was too old and ill. She thinks that too many old people leave the decision until a crisis forces the family to 'decide for us'. No, Mrs Carter decided she would 'make the decision for them'.

She 'really was not ill', but like many people of her age, she was suffering from arthritis. She was getting impatient with doing the

housework and cooking. She had reached the point where 'life was not as enjoyable'. She did not want to become 'a trouble to others'. With this philosophical outlook, she 'went' in a home.

Unlike many other patients, Mrs Carter selected the nursing home she liked. When I asked her daughter about the application details, I was told, 'you really have to ask Mother those questions, we knew nothing about it'. Mrs Carter was 'shopping' for a single room. She lodged several applications and three months later, she received a call informing her of a vacancy. She went out to 'inspect the home', and after a 'good chat with matron', she decided this was going to be her new 'place'.

Does she have any regrets? 'No, my word! It was my wish to get out of my home'. Her arthritis is worse since the move. She cannot imagine how she would have coped at home. Her 'people' could not offer her the care she receives from the nursing home staff. Besides, she told me, 'you cannot count on people to help you all the time'. There is a limit to everything isn't there Vic?'

However, not all of the residents who were living alone decided for themselves to move into a nursing home. A wide diversity exists amongst this group of people in terms of marital status and availability of family support. Table 4.2 also shows that people who lived alone were more likely than people who lived with others to rely on health professionals to assist them with the decision making process. For example, health professionals are called upon to make decisions on behalf of the never married living alone because they are more likely than their married counterparts to have already established contact with social workers or nurses by being clients of community services (Wan, 1982a). Or in the absence of family support, as illustrated by the second case described below, Miss Lyons, they wait until a

crisis places them in the care of health professionals. People who lived alone were more likely than people who lived with others to rely on health professionals to assist them with the decision making process, probably the result of being clients of community services or in absence of family support they wait until a crisis places them in the care of health professionals.

Miss Lyons

Miss Lyons highlights the vulnerability of having others determine the fate of the single aged person living alone and without family. Miss Lyons is 85 years old. She never married and as an only child, lived with her parents until they died. After the death of her mother, Miss Lyons continued to live in the family home for twelve years. She has no family. Her only cousin died a few years ago, and in recent years, her friends, who are also old, 'stopped calling'. Although she was always courteous to her neighbours, her relationship with them never extended beyond the ceremonial greetings. As people were forgetting her, she was also withdrawing from the community.

Miss Lyons never gave much thought to living in a nursing home. She had never 'been to such a place before'. The circumstances surrounding her application were simple. 'It just happened' and she had very little influence in the decision. Her next-door neighbour noticed that Miss Lyons had not been collecting her milk and mail. Worried that Miss Lyons might have had an accident, the neighbour called the police. They found Miss Lyons locked in the garage, holding a gun in her hand. Frightened of being alone at night, she took refuge in the cold, dirty garage. The director of nursing home said that Miss Lyons was found half-dressed and suffering from malnutrition and arthritis. She was rushed to the hospital and a social

worker was assigned to her case. With no family member to assume responsibility, her fate was determined by professionals. The medical team decided that it was not safe for Miss Lyons to return home. Instead they decided to transfer her to the nursing home. Upon admission, Miss Lyons required assistance from the nursing staff with dressing and bathing. The senior nurse noted that Miss Lyons's overall physical health had improved greatly since moving to the nursing home. At the time of the interview, she was able to bathe and dress herself.

Miss Lyons was not upset about being told to move into a nursing home. She could see no other alternative, nor was one presented to her. She had nursed both of her parents at home until they died. She believed that only the family can assist an aged person to remain at home. This is why she never bothered with community services. 'I am an only one as it happens: that is how I got to be in this home'. They had given their medical orders and she was following the treatment.

Miss Lyons does not, however, enjoy living in a nursing home. She feels that she has lost her rights as a human being. 'I can't even go out to buy stamps'. But what can she do about this? 'Nothing really'. 'Who can I turn to for help?', she asks. Throughout her life, she has had to make the best of her situation. She does not have 'a friend left in the world'; that is why her remaining days will be spent at the nursing home.

Conclusion

This chapter has shown that the older person is often a minor participant in the decision to enter a nursing home. Over three-quarters of the residents in this study felt that they had 'very little or no say' in the decision to move into a nursing home. Family members are seen as the most

influential actors, although there were differences in the ways in which actors were selected depending on the living arrangement of residents. This raises an interesting conceptual question about the ways in which older people enter nursing homes. What factors account for the involvement of the aged persons in the decision making process?

The next chapter explores more deeply the process by which older people are excluded or included in decision making. It examines how social situations affect individuals' chances of participating in the decision to seek institutional care, and how this in turn, influences their outlook on life once in a nursing home. Although chapter 4 briefly explored how people are selected to participate in the decision making process, living arrangement is only one of the many factors that influence their pathways into nursing homes. Living arrangement is closely interwined with other factors, such as marital status, health and the availability of informal support. Chapter 5 will disentangle the effects of these factors on the residents' degree of involvement in the decision to enter a home.

CHAPTER 5

A Typology of Decision Making Situations

There are several steps in the decision to enter a nursing home. There is not only the question of making the decision to seek nursing home care, but also one of selecting the nursing home. The older person's subjective well being and adjustment to living in a nursing home can be expected to be influenced by the older person's involvement in these decisions.

The notion of control is central to much of human behaviour. The need to control one's destiny has been described as 'an intrinsic necessity of life itself' (Adler, 1930:398). People strive to be 'causal agents, to be the primary locus of control of, causation for, or the origin of, their behaviour' (DeCharms, 1968:269). Experimental studies dealing with the perception of control have found that exercising personal choice has a definite and positive role in improving their quality of life (Langer, Janis and Wolfer, 1975). However, few studies have examined the relationship between involvement in the decision to enter a nursing home and subjective well being (Thomas, 1986).

Entering nursing homes represents a major life passage for elderly people. Some degree of stress is felt although it may not be experienced in the same manner by all residents (Lazarus and Folkman, 1984; Minichiello, 1986; Tobin and Lieberman 1976). A person's control over the decision to enter a nursing home potentially could be expected to cushion the effects of institutional living. Control refers to the extent to which people see their situation as being contingent upon their own decisions as opposed to it being determined by others. This concept can be applied, as will be shown later in

the chapter, to discriminate between those patients who adjust to living in a nursing home and those who do not.

Equally as important is the older person's involvement in selecting the nursing home. For most older people, the nursing home will be their 'last stop' (Howe, 1983). Having a say in where one will live could well be expected to affect the person's acceptance of their environment. Patients who have no opportunity to visit the nursing home and do not assess the environment prior to placement (e.g., features dealing with privacy, friendliness of staff) may not like or accept the choice.

The two steps of the decision making process in entering a nursing home may be conceptualised jointly, as illustrated in Figure 5.1. The first decision is whether or not to enter a nursing home. The second is the choice of a nursing home. The typology presented in Figure 5.1 shows that residents' differed in their level of involvement in the decision making process. The upper left hand cell shows that a minority of residents were involved in decisions both to enter a nursing home and in its choice. The lower right hand cell shows that a majority of residents were totally excluded from the decision making process. The other two cells illustrate the small numbers of residents who felt they were partly involved in the decisions to enter a nursing home.

This chapter will examine the processes leading to the decision making situations outlined in the above typology. The discussion will focus on identifying the factors which explain why older people vary in their involvement in decisions to enter and select a nursing home.

Figure 5.1 A typology of the aged person's degree of involvement in seeking nursing home care and number of residents in each cell (N=90).[a]

Involvement in the Decision to Move into Nursing Home	Involvement in Selecting Nursing Home: YES	Involvement in Selecting Nursing Home: NO
YES	Fully Involved: 19	Decision Involved: 10
NO	Selection Involved: 8	Excluded: 53

(a) To determine their involvement in the decision making process, residents were asked two questions : 'How much say did you have in the decision to move to a nursing home?' and 'How much say did you have in selecting the nursing home?' The residents' replies to these questions were then compared to those of their next-of-kin. In only two cases were the replies from residents and their kin in conflict with one another. In both cases, the resident reported having some say in the decision to enter a home while their next-of-kin reported that the older person had no involvement. In order to overcome this discrepancy, the director of the nursing home was asked her opinion as to whether the older person was involved in the decisions to enter and select the nursing home. Discussions with the director confirmed the relative's view that the older person had been excluded from the decision. When I sought further clarification of their role in the decision making process, both residents changed their stories about their involvement.

Residents who were Fully Involved

Residents who were responsible for seeking and arranging their own admission are classified as 'fully involved'. Of the 90 residents interviewed, 19 were responsible for their own admission. These are residents who were nominated by themselves and their next-of-kin as the most important player in the decision making process, as well as being the person who contacted the director of the nursing home.

The influence of gender, marital status, living arrangement and health on the ageing experience has been explored in a number of studies (Troll et al., 1979; Russell and Schofield, 1986). These factors have an interactive influence on each other and lead to different types of negotiations between the older person and their family about how to manage old age (Kendig, 1986). These factors have also been cited in explaining why older people hold different expectations about the use of formal and informal care (Day, 1985). For instance, 'those who never married appear to develop very different orientations, personal skills, and support networks' from those of the married, widowed and divorced, and as a result come to rely on different forms of care arrangement. (Kendig, 1986:10). They are more likely than the other marital groups to plan ahead as a way of establishing some protection against old age (Day, 1985). While there can be no doubt that these factors can constrain or enhance people's options about care arrangements, individual action is not solely determined by them. People possessing similar social characteristics can and do display different attitudes towards the use of formal and informal care. This may partly explain why studies have found these factors to be poor predictors of the use

of community and institutional services (Coulton and Frost, 1982; McAuley and Prohaska, 1982). Their interpretation and assessment of the situation also will influence their reaction to their predicament. Thus, as shown in the case study of Miss Barber (see p108) and Mr Hollier (see p133,137) presented below, it is possible for people to be faced with a similar situation (eg., no children) but because they hold different perceptions of their situation they will respond differently.

Table 5.1 shows some of the key social characteristics of residents in the different types of decision making situation. Of the 19 residents who themselves decided to move into a home, five residents were never married, four were married and 10 were widowed. While for some residents the absence of children was the underlying factor which forced them to consider institutional care, there were other residents who had the potential support of children and other family members. Seven of these residents had children. Although the majority were living alone, eight were living with family members or friends. As will be discussed below, family members had offered some of these residents an alternative to nursing home care. It is also worth noting that the absence of a child is not a prerequisite to making up own's one mind to move into a nursing home. Of the 53 residents in the excluded category, 17 were without children but they nevertheless did not anticipate or choose nursing homes as a viable option.

There are some clear differences between people who were involved or excluded in the decision making. Those who were fully involved were more likely to be in better health prior to admission, independent and self-supporting. In fact, their most striking difference from other residents

Table 5.1 A profile of the residents with different levels of involvement in the decision making process by age, gender, marital status, health, living arrangement, source of help when living in the community and subjective well-being

Profile characteristics	Involved	Decision Involved	Selection Involved	Excluded
Number of Respondents	19	10	8	53
Gender				
Male	4	4	2	13
Female	15	6	6	40
Marital status				
Never married	5	2	-	12
Widowed	10	4	8	29
Married	4	4	-	6
Divorced/separated	-	-	-	6
Living arrangement				
Alone	11	6	4	25
With others	8	4	4	28
Source of help[a]				
Self	13	-	-	19
Informal	4	6	8	21
Formal	2	4	-	13
Mean Age	85	83	83	79
Mean functional health[b]	22	36	24	27
Mean happy score[c]	1.7	2.0	2.4	2.5

a Respondents were asked to nominate the person who did most of the shopping, meal preparation and housework when living in the community. The Informal sector includes family members, friends and neighbours while the formal sector includes paid help, and community and government agencies.

b This score represents the person's ability to perform 18 activities of daily living. A score of 18 indicates that the person was capable of performing all of the activities of daily living while a score of 72 indicates that the person was not capable of performing any of the activities when living in the community.

c Subjective well-being was measured by asking respondents the following question, 'Taking things altogether, how would you say things are these days? Would you say that you're happy, fairly happy, or not happy?' A score of 1 indicates that the resident is very happy while a score of 3 indicates that the resident is not too happy. Significant differences in the level of happiness were found between the four groups ($F=12.8;p<.000$).

was their orientation towards this self-management and positive attitude to informal care. Of course, the good health of the involved entrants prior to admission could partly account for their independence. Yet health alone can not explain why these people did not rely on others to help them with household and personal tasks. Their self perceptions were important in shaping their outlook on care arrangement. They held a strong view about not accepting help from others. The following quotes highlight the residents' determination to remain independent of their families in their old age.

> I would not go and live with my daughter. I have always preferred to be on my own, to be independent and make decisions for myself. The thought that I could become dependent on my people, like my mother was on us, scares me. This is why I decided to come here (Mrs Hodges, widowed, 89 years old; see pp 51,65).

> I made the decision to come here because I prefer this arrangement than living with my family. I like my children and they like me. But I have always said that when I could not look after myself, I would go to a home. My children have never interfered with my life. And I would not want to keep them from living their life (Mrs Carter, widowed, 84 years old; see pp 54,94).

The majority of these residents had been living alone. They preferred this living arrangement because of the mutual obligations placed on people when they share households.

> When my wife died my daughter asked me to go and live with her. I was touched by her offer but told her that I could not accept it. Mt wife and I have always lead an independent life from the children. I did not want to give up my little ways of doing

> things because when you go and live with your children you have to change. And I was not prepared to give up my independence. My daughter was concerned because my wife did all of the cooking and housework and she thought that I would not cope. Well I gave it a good battle for three years and then I decided to move into a nursing home when I felt a little tired (Mr Greenwood, widowed, 70 years old).

Of those who had been living with others, none were living in what they described as a 'dependent relationship'. Help was reciprocally and voluntarily given and received.

> I was not a burden. We all shared the work. We never asked our neighbours to help because between us we could manage (Miss Kaye, never married, 84 years old; pp 75).

> I lived with my daughter for 5 years but I looked after my own room and did my own cooking. In fact, because my daughter was working part time I would sometimes prepare the family meal or help her peel the vegies or wash up (Mrs Desmond, widowed, 85 years old).

Many of these residents were living with people of a similar age. Shared living was seen to be a way of combating the dependency brought about by old age.

These residents spoke about their self-sufficiency. When they were asked to nominate the person who did the major household and personal tasks just prior to admission, all but three of the 8 residents who lived with others stated that they were responsible for or jointly shared these tasks. The three residents who had relied on outside help were married men whose wives were in hospital. Their wives had always done 'such chores'. Lacking the necessary skills, they relied on other female family to assist them with

cooking, shopping and house cleaning. Although grateful for the help, they interpreted it as an intrusion into their personal lives. Once they realised that their wives would not be returning home, they 'exited' from this dependency relationship by admitting themselves as well as their partners into a nursing home.

> I did not like my daughter coming in and helping me. My wife and I have always been very independent. We never asked our children for help. The doctor asked me if I would consider getting Meals-on-Wheels when my wife was in the hospital. I refused. I wouldn't want other people coming into my house. If I could do things myself I would do them. I like to be independent. And this was why I found accepting my families help so difficult. For one thing, I never expected it. And when someone is helping you, there is a sense of owing them something. My daughter would prepare a meal when it was convenient for her. And although it was not when I wanted to eat, I felt that I had to because it was a big effort on her part (Mr Jukic, married, 93 years old; see p 69).

Two case studies are presented and discussed to highlight how the residents' personal orientation and perception of their social circumstances influenced their involvement in the decision to enter a nursing home.

Miss Barber

Miss Barber is 78 years old and never married. She lived with her sister for 20 years. When her sister died, Miss Barber moved into a flat. She lived alone for the next 10 years.

During the last few years, Miss Barber experienced problems with her eyesight. She went to see her doctor, who confirmed that she had vision impairment in her right eye. It was at this stage that she began to plan for

her old age. Although she was capable of independent living and did not require help with any of the household and personal care tasks of daily living, Miss Barber became 'aware that I was old'.

It was because she did not have any children 'to look after me' that she considered moving into a nursing home. Her only relation was an older brother. He was 'too old' to help look after her. Looking for security, the nursing home was her only alternative.

> How do I know what might happen to him?. Anything could happen to him and then I'd be left on my own. Out in the cold, you see. And I was trying to avoid this situation from happening.

She discussed her decision with her brother. It was only after she had selected the nursing home that she consulted a physician. She required his signature on the administrative forms.

With the help of her brother, she went 'shopping' for a home. They visited a total of 10 nursing homes, and although she placed her name on several waiting lists, she was 'only interested' in Nursing Home A. Miss Barber was impressed with this particular home because of the friendly staff, the cleanliness of the home and its close proximity to her brother's residence. Not under any pressure or urgency to move quickly, she waited eight months before a vacancy occurred at Nursing Home A.

The number of nursing homes Miss Barber visited and her reason for selecting the nursing home are consistent with the experiences of other residents who were fully involved in the decision to seek nursing home care. In the search for a nursing home, residents who were fully involved contacted a mean of 9.4 homes. After lodging their application, they waited

a mean of 3.4 months before placement. The most frequent reason for selecting the home was the availability of a single room, the friendliness of staff and the homely features of the home.

When Miss Barber was asked the question 'what did you think about moving into a nursing home', she replied, like the other 18 residents who fully participated in the decision, that she 'was very much in favour of the move'. Although at the time of her admission she was capable of independent living, she realised that eventually she would be dependent on others. Unable to muster informal support in the community, 'what else was I to do'. She was not prepared to wait and let others decide her future. A crisis, she said, would take away any opportunity she had to determine her own fate. Having lead an independent life and always made decisions for herself, she made the most of 'her chance'.

She ended the interview by saying that although it is never easy for people to come and live in a nursing home, this decision is more acceptable if 'it is your decision'. Miss Barber considers herself 'lucky'. She 'sat down and examined her options' before someone else did it for her. Unlike many of the other residents, the move was planned. She had time to think about and come to terms with institutional living.

Mr Hamilton

Couples who have lived together for 50 or so years often turn to each other for personal support without apology, blame or anxiety about having to reciprocate services received (see p 69). When they are separated, however, they face a kind of vulnerability that those who have

long lived alone have either faced or come to terms with much earlier in their lives (Day, 1985). As chapter 3 illustrated older males are particularly vulnerable to change in their living arrangement when their partner dies or moves to a nursing home.

Mr Hamilton, who is 87 years old, found himself in this situation when his wife had a stroke and moved into a nursing home. Although he tried to live on his own for 'almost a year' he decided that it would be easier to resume life if he also moved into the nursing home. There are two factors that help to explain why Mr Hamilton decided to move. Firstly, he had a strong bond with his wife and wanted to be 'with her'. Secondly, he did not want to be a burden to his children.

Mr Hamilton has a close emotional bond with his three children; a son who lives in Sydney, and a daughter and older son who both live interstate. Although he relies on his children to make him feel needed and appreciated, he and his wife have never been dependent on them for instrumental support. Throughout the years it was they who were providing help to their children. When his wife had the stroke, there was no uncertainty about what they should do. The choice was obvious. Nursing home care would allow them to continue enjoying their independence from the family. After discussing their situation with the doctor, they jointly made the decision that Mrs Hamilton would move into the nursing home. Mr Hamilton would 'try' to live on his own.

For the next six months Mr Hamilton lived alone and did most of his own cooking, shopping and house cleaning. He would only reluctantly agree to accept help with the housework from his daughter-in-law or help with the

gardening from his son and grandsons. His sister and children often invited him to 'stay with them on weekends'. However, it was only on 'very special occasions' that he would accept their hospitality. When asked why he did not use community services, he replied that he preferred not to use them. His neighbours and friends also offered to help him with the housework and gardening, 'give me a yell they often would tell me', but they never pressed the issue when he politely said no. They respected his independence. As a minister, he saw his role as helping and not receiving help from others.

Although Mr Hamilton nominated his eldest son as the person he turns to if he needs someone to confide in, his wife is his closest friend. When she moved into the nursing home, so did part of him. Without her presence close to him, he felt lonely and living 'without a cause'.

While living alone he visited his wife every day and had lunch and tea at the nursing home. 'I spent most of my time with her; helping feed and bath her'. His son and daughter-in-law were concerned that Mr Hamilton was not looking after his own health. Between traveling from his home to the nursing home, looking after the house with little help from others, and learning how to cook and attend to domestic chores his children felt he would 'also have a stroke'. He often 'looked tired' and no longer was the cheerful person his family knew him to be.

Mr Hamilton was also concerned about his health and had been thinking about moving into the nursing home. When the senior nurse and doctor informed him that his wife would not live for much longer, he admitted himself to the nursing home. He wanted to be close to his wife

when she died. It was his own decision. He discussed the subject with his children and inquired about a vacancy. A few weeks later he joined his wife.

Mr Hamilton was given a separate room from his wife. This did not upset him. He understood the house rules of bed planning. He spent most of his time helping the nurses look after his wife and 'being by her side'. Six months after his admission, his wife died. Because her departure was gradual, he had come to terms with her death.

During these months, Mr Hamilton thought about his future plans. He was in good physical health and required no assistance from the staff. He often helped the handyman with the light repairs or replacing light bulbs. But he was looking ahead. His wife's death reminded him that he was getting old. He was 82 years old. Foremost on his mind was that he did not want to be a burden to his children. When Mrs Hamilton died, his children did not ask him to move in with them. Like his neighbours and friends, they understood and respected Mr Hamilton's desire to be independent. Besides he had come to enjoy living in a nursing home. He spoke highly of the staff, the food and physical surroundings. The other residents made him feel needed. He often read and wrote letters for the more disabled patients. At the nursing home he could continue playing the role of helper. Living in the community had taken away this role. Equally as important in helping him decide to remain at the nursing home was that he felt that there was no point returning to his home. In the event of an accident or illness he would be forced to leave his home.

Lessons from Residents who were Fully Involved

Common factors in the stories of Miss Barber and Mr Hamilton, as well as other residents in this category, were their good health on entry to a nursing home and their life long independence from others. Good health not only makes it possible for the older person to travel to the nursing home and be involved in the administrative arrangement of seeking nursing home care, but also reduces the chances of being placed in a situation of dependency prior to admission. One of the costs a person must pay for seeking help is the obligation to comply with the advice given by helpers. It requires the surrender of a certain amount of self-determination, as the person is placed in a sick role (Parsons, 1951) that assumes dependency on others. None of the fully involved residents found themselves in situations where they had given others the right to determine their fate, nor were any of them prepared to be placed in such situations. Realising that 'time' would eventually place them in a dependent relationship with their family or friends, they made the decision while they were still 'in the driver's seat'.

'Forward planning' or 'crisis decision making' typifies the nursing home decisions. Forward planning, as illustrated by Miss Barber, can involve the conscious decision by the older person to find 'a home', but, not all of the fully involved residents were planners. Of these 19 residents, 10 made a forward planning decision, while the others had not thought of moving into a nursing home until a crisis forced them to consider institutional living. As will be discussed below, the involved entrants who found themselves in a crisis differed from the excluded entrants in their

strong determination to remain independent. It was for this reason that they took the initiative to move into a nursing home.

Forward planners appraised their social situation in terms of family support, or lack of family support, and their self-care abilities as they grew older. A striking feature of the forward planners was their perception and often the fact of having limited family support available to them. Four of the ten forward planners were never married, four were married without children and two were childless widows. They searched for clues that helped them determine 'when the time had come'.

> I lost my motor car and I thought well this is a sign that it is time to go into a home. I never wanted to worry my grandsons so I decided not to tell them about my plans. (Mrs Alkins, widowed, 88 years old).

Some had already set a deadline as to when they would move. They obtained nursing home care as security. Many of these people did not initially require the extent of care provided by the nursing home but limited by their options, they had no other choice.

> I was quite able to look after myself but I decided to put my name down. Because I had no children I thought that when I got old it would be nice to be looked after. I was 85 years old and I put my name down. I did not think I would get in for years but I was accepted in 6 months (Mrs Bennett, widowed, 87 years old; see pp 55,65).

Included residents who made a crisis decision varied in the circumstances that led to moving into a nursing home. The illness of a

spouse, the onset of an acute illness or a change in living arrangement initiated thinking about moving into a nursing home. All had given thought to this option because they wanted to avoid entering into a dependency relationship with family members or friends. As is illustrated by Mr Hamilton, they found the nursing home solution 'acceptable' because they did not want to burden others. Family support was an option for most of them but they chose nursing home care. The decision was made on behalf of both the family and themselves.

> I felt that moving into a nursing home was loyal to my family. I can't see now. I couldn't put that responsibility on my children. They have families of their own (Mrs McCoppin, widowed, 72 years old).

The family never assumed the constant worry of the caregiver role; the older person never became 'a worry'. The vicious cycle of dependency, which characterizes the nature of many relationships between old people and their families, was never allowed to surface.

Because these residents held the view that they were selecting a 'home', they were all concerned about locating 'the right place'. For most, this involved a number of visits to nursing homes. For others, the search had begun many years earlier. Planners were more likely than the other residents to 'take their time' when searching for a home as they were not restricted by a crisis situation.

Institutional care was selected to avoid becoming dependent on others for companionship and care in the future. They entered the nursing home voluntarily and this made it easier for them to accept institutional life. When these residents were asked about their feelings regarding the move,

none spoke of the apprehension and fears that characterised the stories of residents who were excluded from the decisions. All 19 residents selected words such as 'accepting' and 'security', which suggests that they had come to terms with their decision. 'No regrets, no point looking back'.

Residents who were Excluded

The 'excluded' are those residents who were not involved in the decisions to seek institutional care or in choosing the nursing home. Of the 90 residents, 53 saw themselves as silent parties in the decision making process. When asked who made the decisions, these residents nominated people other than themselves.

None had visited the nursing home prior to admission or were able to recall the administrative details of the application. The following quote is representative of the level of knowledge these residents had about who contacted the director of nursing home and whether applications to other nursing homes had been lodged.

> Vic: Could we now talk about your application to the nursing home?
> Mr Osborne: Well I never applied to go to any nursing home. I really don't know anything about that. My son would have done all of that.
> Vic: Do you know why he selected this nursing home?
> Mr Osborne: I can't answer that truthfully. The only thing I know is that he came in one day and said I was coming here (Mr Osborne, widowed; 75 years old; see p 61).

Who are these excluded residents and can we detect any similarities in their situations prior to admission? Table 5.1 shows that they differ in

many ways from the involved residents. The excluded residents had decisions made for them at a time when they had deteriorating health and were dependent on others. They generally were in much poorer physical health than the included residents. Excluded residents waited until their health situation deteriorated or their caregivers could no longer manage.

> Mrs Newman: My husband died and I lived alone for twelve months. I had been living alone for some time and I wasn't really feeling well. My daughter had been helping me with the housework. I had an asthma attack and the ambulance took me to the hospital. It was while I was in the hospital that I was told by my daughter that I was moving into a home (widowed, 83 years old).

> Mrs Newman's daughter: Even before my father died I was worried about her. I helped her nurse my father. But she also needed help. I used to spent a lot of my time running to her place. I am an only child but our house is not big enough to have her live with us. When she went into the hospital I made the decision (married, age - 50s).

Table 5.1 shows that the majority of the excluded residents had been dependent on informal and/or formal support to complete the tasks of daily living. When we look at who did most of the shopping, meal preparation and housework, over two thirds of these residents were relying on either family members or community services. They used formal services for an average of 12 months and informal services on the average for the last 23 months prior to admission. Not only had they become dependent on using formal or informal help, but they were also more likely than the included residents to have been living with others prior to admission. More than half of these residents were living with others, usually a child. The passage from self help to having to rely on others can generate a sense of anomie

amongst the aged (Townsend, 1981). Once a person enters into a dependency relationship, 'both they and those responsible for their care see the drift into greater dependency as irreversible' (Day, 1985:112). Family members (in chapter 3) spoke about nursing homes as the only alternative to home care after family support had failed.

Another distinguishing feature between these two groups was their outlook towards future care plans. While the included residents had ruled out relying on family support, excluded residents were more likely to expect families to provide long term support. Many had cared for their own parents at home and had seen them die in an acute hospital. Based on their past care experiences, they expected a similar fate.

> I never thought I would end up in a nursing home. Just like my father and mother, I thought I was one of these people that would go on doing things for myself or have my family look after me (Mrs Cocke, widowed, 89 years old).

They believed that it was not necessary to make plans because their families would look after them if 'there was a need'. Day refers to these people as 'counters on family support'.

> ...not only did [they] believe that their children would be available to give personal care when needed, but they accepted the appropriateness of this filial obligation. (T)hese parents apparently welcomed without shame, fear or ambivalence their children's offers to provide the last-ditch custodial care (1985:120).

Formal services were not seen as a substitute for family care. They held the expectation that between themselves and their families they could

manage until 'the end'. Few ever expected to live their remaining lives in a nursing home.

> I never thought I would end up in a nursing home. I feel my children have let me down. I would never have put my parents in a nursing home -- people just didn't think of doing that and I know of other younger people who are looking after their aged parents (Mrs Telling, widowed, 72 years old).

Many of these residents spoke about how the 'family has changed' and that the younger generation is less willing to care for an aged parent. Yet as we saw in Chapter 3, family members do want to provide care, however, they find it difficult because of the effects of social changes on people's ability to provide parent care. For instance, people in the first half of the twentienth century were less likely to provide long term care support for their aged relatives as many more older people died at an earlier age. Uhlenberg (1980) shows that the number of people who experienced the death of a parent before the age of 15 dropped from one in four to one in 20, while the number of middle aged couples with two or more living parents increased from 10 per cent to 47 per cent. Not only do we now have more children in their late fifties with surviving parents, but there has also been a change in the nature and duration of care. Chronic illnesses have replaced acute diseases in accounting for most deaths. As a result of this major shift in emphasis from acute to chronic care, and older people living longer, families are required to offer more care for longer periods of time. Many of these residents failed to understand that a different form of care was required to maintain them at home than the care provided in the 'good old days'. Whereas their family members came to grips with the

difficulty of providing long term care, the older person held on to the view that 'everything will work out'. Holding contradictory views on what the family should and could do, and finding it difficult to raise the topic of nursing homes with their aged relative, family members excluded the older person from the decision making process.

> Mrs Aroni: I thought I was managing quite well. I use to get my cleaning done and my daughters and meal-on-wheels would help me with the cooking. But my daughters did not think it was wise for me to stay home alone. They told me I had to come here. When I first came here I used to cry and go to see matron and tell her that I wanted to return home, and matron would say I can't unless the daughters gave their consent (widowed, 91 years old).
>
> Mrs Aroni's daughter: My mother is 91 years old and she was losing her eyesight. She used to say she was all right but she wasn't. She would not eat properly. At the time, my sister and I both worked and we would call by to see her every day. But the situation was getting worse and we could not continue the pace. We couldn't talk to her because she thought everything was fine. So we decided to put her in a home. We did not think it was safe for her to live alone (married, age - 60s; see p 53).

People in this category often waited for a major crisis before making the decision to seek nursing home care. Of these 53 residents, 32 were admitted after an illness placed them in an institutional setting and six residents after they had experienced a change in their living arrangement, such as the death of a spouse or being evicted from their flat. Family members often waited until they felt they could no longer maintain the older relative at home (see chapter 3). Hospitalisation was for some residents the final signal for a change in care arrangement. The remaining eight residents were admitted after family members were no longer willing to

continue providing support. It is interesting to note, however, that family members fight hard to maintain the older person at home. Most waited until the situation required some drastic measure to be taken. As the stories of family members illustrated (in chapter 3) the decision to institutionalise an aged parent is not an easy one.

The crisis placed the older person in a position where their future was governed by forces beyond their control. Family members and health professionals were called upon or took it upon themselves to act on behalf of the older person. A quick decision had to be made. Family members used this opportunity to make a decision they had postponed many times in the past, while health professionals made the only recommendation they thought was possible given the failure of formal care in the community and/or family care (see chapter 4).

Residents who were totally excluded from the decisions to enter a home came from a variety of living arrangement contexts and family situations. To highlight how these factors influenced the exclusion of the older person from the decision making process, three case studies are presented and discussed.

Mrs Young

Mrs Young had been living with her daughter for over three years before entering the nursing home (see p 72). When her husband died she had asked her daughter, who was going through a separation, if she could go and live with her. Mrs Young's daughter agreed. Mrs Young then sold her family home and looked forward to living with her daughter, but the

experience was unhappy for both. Her daughter worked and was seldom home. 'I used to sit at home and wait for my daughter to arrive. She was the only person I would see and talk to'. Mrs Young's daughter resented feeling guilty about leaving her mother alone. 'When I would leave she would jump into the lounge and sleep all day'. She felt her mother was not trying 'hard enough' to lead an independent life. 'She made no attempt to find friends or go out on her own.' Mrs Young held a different view. She felt that her daughter was not very supportive. 'I do not understand why she was always busy with her work and friends and never bothered to find time for me'. She expected her daughter to give her more companionship and attention.

It was not Mrs Young's decision to move into a home. 'It all happened so quickly. I did not even know she was thinking along those lines'. One day Mrs Young's daughter announced that she had spoken to a director of nursing home and lodged an application. 'She told me I had to go'. Mrs Young was given no opportunity to have a say, and was devastated. She had a fight with her daughter and accused her of being selfish. Mrs Young could not understand her daughter's actions. After all, she would never have considered putting her parents into a home.

Mrs Young did not think she was a nuisance. She required very little help from her daughter with household and personal tasks. Other children were looking after parents who were much more dependent than she was. And her daughter had no family of her own even to worry about. She did not want to move but her daughter insisted. 'I was in shock and did not even think about asking her if I could see the home'.

A week later she moved into the nursing home. Mrs Young has found it very difficult to cope with being in a nursing home. She had never thought about the possibility, and can not forgive her only daughter for doing this to her. She fears that dying will take a long time. Whenever her daughter visits she asks if she can return home. This request makes the visit even more uncomfortable for the daughter. 'When I visit mum we mostly argue so I do not go as often as I should'.

Mrs Earl

A widow of 15 years, Mrs Earl lived only a few kilometers from her two married sons (see pp 80,81). She had never thought about living in a nursing home until she found herself in the doctor's office. Her sons and the doctor had made the decision for her. When it was first suggested that she move into a nursing home Mrs Earl cried and told her sons that she would not 'abandon' her home.

Her sons do not feel close to their mother. Mrs Earl never asked them for any help, and did her own cooking, shopping and housekeeping. The grocery boy delivered her errands and she hired private paid help to do the gardening and house repairs, nor did she ask her neighbours for assistance. She had few friends. 'I did not want any help'.

Mrs Earl had become a diabetic but had not told her sons. She had not been eating properly or taking her medication regularly. She often had dizzy spells and would collapse on the floor. Her daughter-in-law noticed bruises on her arms and legs, and was also worried about her mother-in-law's weight loss. She informed her husband and an appointment

with the doctor was arranged. The family was told that Mrs Earl had sugar diabetes and was suffering from malnutrition. Without immediate care and supervision, her medical situation would become critical. This news alarmed the family.

Her sons suggested that she receive Meal-on-Wheels and home nursing. But Mrs Earl would 'not allow it'. She regarded the community services as charity. If the family could not help her then 'no one else could'. A few weeks later another doctor's appointment was arranged. The family was informed that unless Mrs Earl received care she was in danger of dying. She had lost six stone. 'Something had to be done'. After much discussion, her two sons and daughters-in-law agreed that they were not prepared for her to live with them. The family recognized that Mrs Earl did not require much personal care. But this was not the problem. Her personality and past family history were important factors in her children ruling out accepting her in their homes. Of course there were other problems. They had young children and their homes 'did not have the space'. These were complications which could have been overcome if the family felt closer to her, but time had taught the family that Mrs Earl was a 'difficult person' to get along and had 'always been so'.

> I don't mean to complain about her but she has many problems; too many for one single person. We have too little patience to tolerate her (daughter-in-law, married, age - 50s).

Could they have helped Mrs Earl cope in her own home if they provided a little more support? They tried for a few weeks but there was only so much help they could offer. Mrs Earl's sons were working, her eldest

daughter-in-law was raising two young sons and the other daughter-in-law worked and had a 'poor' relationship with her mother-in-law. As far as her family was concerned the nursing home was the only solution. With the help of the physician they searched for a nursing home bed. They were not selective. They admitted Mrs Earl into the first nursing home that offered a bed. Mrs Earl never 'saw or heard of the place' until her sons 'brought me here'. She had nothing to do with the decision. Her sons had not discussed their plans with her. With the help of the doctor she was told to move into a nursing home.

Mrs Earl finds it difficult to accept living in a home. She was 'very much opposed' to moving. She does not get along with the other patients or participate in any of the activities. If another patient screams at night Mrs Earl complains. Her sons are worried that the director of the nursing home will ask them to find another home. Since moving to the nursing home Mrs Earl's relationship with her family has 'got worse'. Her daughter-in-law said that the last 'six months have been hell'. They visit only when 'it is necessary'.

Mr Barclay

Mr Barclay is 70 years old and had never married. A loner throughout his life, he drifted from one boarding house to another. He had few friends. Although he has two brothers and three sisters living in Sydney he has not kept in touch with them 'for years'. He lost contact when his mother died twenty years ago. He said he feels close to no one.

Life took a drastic turn for Mr Barclay when he retired from his railway job. Or at least, life after retirement was different from what he

expected. Without a job to go to, he no longer felt useful. His days were filled with too many hours and little to do. He was also having problems with his eye sight. He postponed seeing the doctor until his cataracts got progressively worse, and he could no longer read the newspaper or watch television. The only reason he went to see the doctor was because it was arranged by the social worker, and she and the doctor later suggested that he move into a nursing home. They explained to him that he would require constant care after his cataract operation, and that the doctor would not operate unless Mr Barclay moved into a nursing home.

Mr Barclay had never thought about living in a nursing home. In fact, he held some very negative views about old people living in nursing homes.

> Some of them are like hovels. All they are interested in is taking old people's money. The government has closed some of them down because of abuses to patients, for ill treatment, neglect and all that ugly business. Well I was very wary of them.

But as there was nowhere else for him to go the social worker arranged for his admission. It was the social worker who announced to him that he was moving into a home. 'I was not given a choice'.

He was not happy about the social worker's decision. He knew nothing about nursing homes nor did he ever visit the home prior to his admission. When I inquired further about how the nursing home was selected he replied angrily:

> You just do not walk into places like this. You go to the doctor and he makes inquiries. It works just like going into a hospital. You just do not arrive at their doorsteps and say you want a bed. I did not choose to come here. They sent me here. If I had my way I would still be living in a boarding home.

Lessons from Residents who were Excluded

Alienation from the decision making process and feelings of powerlessness and helplessness were the common themes that emerged from the stories of the residents who were excluded.

> Vic: Who told you about (nursing home)?
> Mrs Yates: Well no one. I had never heard of the place until my son brought me here.
> Vic: How did you feel about this?
> Mrs Yates: I never thought my only child would ever suggest such a thing. But what was I to do? I was living in their house and he was telling me I had to go. I did not have a choice. I was heartbroken (widowed, 68 years old; see p 74).

Unlike the residents who were totally involved with the decision, none of the excluded residents had ever considered institutional living. They held a derogatory view of nursing homes. 'Such places' were not for them but forother 'poor souls', usually people who had no family ties or who had been abandoned by their families. Like Mrs Earl, many of these residents did not recognise that they were not managing and a burden to others. However, there were differences in how the concept of 'burden' was used. Mrs Earl was 'a burden' to her family because they could not 'get along with her'. This was the reason why they did not offer help. Other family members, like Mrs Young's daughter, felt their parents were 'a burden' because they were being asked to provide more support than they could manage.

While their family member saw many signs of the older person not coping with independent living, the older person held a different interpretation of their situation. They believed that they could simply go on

living the way they were until they would die. For this reason family members found it difficult to raise the topic of nursing homes with their aged relative. Many family members waited for a crisis before taking action. When the opportunity arose, the decision was made quickly and excluded the older person. Often nursing homes were selected on the basis of the availability of a bed rather than on an assessment of the services and environment. The older person was 'surprised' and unwilling to move. None of these residents said they favoured the move.

Those residents without family ties, like Mr Barclay, also waited for a crisis. Although they may have given some thought to nursing home care, they postponed making the decision. Without the support of an informal network, and in the midst of a crisis, they had no choice but to put their fate in the hands of health professionals. This inevitably meant moving into a nursing home. When asked how they felt about moving into the nursing home, they all held mixed feelings about the decision. On one hand, they never wanted to move into a home. On the other hand, it was a necessary decision because they had no family. In many ways they hold similar views towards planning for their own care as the people Day (1985) refers to as fatalists. Fatalists, in her view, did not believe in planning ahead and avoided thinking about what their needs would be when they could no longer manage. They believed that the 'future is governed by forces beyond their control' (Day, 1985:117). If it was left up to them they would have preferred living as they always had. Unfortunately they had incorrectly assessed their situation and others felt they had to plan for them.

Partial decision makers

The involved and excluded situations represent the extremes of the older person's involvement in the decision making process. Some residents, as shown in Figure 5.1, played a partial role in the decisions. They were directly involved in making the decision either to enter a home (decision involved) or to select a home (selection involved), but not in both decisions. Table 5.1 provides a profile of these two types of residents: those who were involved only in the actual decision to move (decision involved) and those who were only participants in selecting which home (selection involved). In general, they were widowed and dependent on family or friends to assist them with the activities of daily living prior to their admission. However, these figures mask a number of differences found between these two types of partial decision makers.

Table 5.1 shows that the 10 residents who had a say in moving to a nursing home but not in selecting the home were in poorer health than the eight residents who were only involved in selecting the nursing home. All 10 of the 'decision involved' residents were admitted from a hospital. Their poor health and, the fact that they had not made prior plans to move into a nursing home, explains to a great extent why they left the decision to select a home to others.

> Vic: Why did you not visit the nursing home before moving into it?
> Mrs Davies: I would have but I was in hospital and it was not possible. So I asked my daughter to make all of the arrangements. But it was not her decision. I made the decision to go into a nursing home. She just helped me find one (widowed, 84 years old).

As the case studies below show, those who were 'decision involved' expressed many similar views about self-care and family support to the involved residents; whereas the residents who were 'selection involved' made similar statements about family care and nursing home care as the residents who were totally excluded from the decision making process. Some differences, however, exist between those residents who played a partial role in the decision and those residents who were either totally involved or excluded from the decision. While the involved residents had ruled out receiving support from their family members, the residents who were 'decision involved' were more ambivalent about the type of care they expected in old age. Prior to their admission, six of these residents relied on family members to do most of their cooking, housecleaning and shopping, and four relied on formal services. These residents were very similar to the 'procrastinators' that Day describes in her study.

> ...(they) were all people in frail health who knew it would be wise for them to make contingency plans, who were aware of various services for the aged, but who had made no move to adopt any of the possible alternatives (1985:116).

They preferred to hold out and adopt a 'wait and see' attitude (Day, 1985). Although they had not committed themselves to institutional care while they were in good health, with the onset of further dependency on others they took the initiative by involving themselves in the planning process.

> I was getting old and couldn't do the things I used to do. I became very dependent on my children. My sons were worried about me. They wanted me to go and live with them. I wasn't happy about that. I went into hospital and my son was going to convert his house for me. But I decided it was not what I

> wanted. I thought, well the best of friends get a bit cross with each other at times so I decided that I was going to a home (Mrs Jones, widowed, 87 years old).

While the suggestion of nursing home care may have been raised by others, these residents made a clear choice in reclaiming some self-determination in the decision. They spoke about the problems they were creating for others.

> The most important reason for making the decision was because I was a lot of trouble to my wife. When I discussed it with her we both agreed that this was the best solution (Mr Kirby, married, 78 years old).

It was this recognition that permitted them to hold discussions about nursing home care with their family members. Because of their involvement in these discussions they saw the decision as resting largely in their hands. When they were asked how they felt about the move they spoke about being 'very much in favour' of moving and the necessity of such a move. They delegated the task of selecting a home to someone they trusted. None complained about the nursing home being selected on their behalf.

> I was in hospital but my sister searched for a nursing home. I had total confidence in her judgement. She is a fussy person and if she thought the place was fine then I knew it would be okay. And she couldn't have chosen a better place (Mr Smith, never married, 90 years old).

Residents who had others make the decision for them but were involved in the selection of the home had no perceptions of the difficulties they were creating for others.

> When my wife died my daughters helped me with the cooking and housework. I did not think I was too much of a trouble. They helped me one day a week. They would come to the house and clean the place, do the washing and all that sort of thing. During the week I managed on my own. I was surprised when my oldest daughter told me that I had to move into a home (Mr Hollier, widowed, 86 years old).

In all 8 cases, family members were doing most of their cooking, housecleaning and shopping and four of these residents had been living with a family member. Relying on their family members to look after them, they had no inkling that others were thinking about nursing home care for them. The one thing that was clear throughout their stories was that they themselves were not thinking about nursing home care.

> I never thought about nursing homes before my daughter suggested to me that I come to one (Mr Hollier, widowed, 86 years old).

There was a certain amount of trauma when they were told about the decision. A 'bargain' was struck between the older person and their family members. In return for agreeing to move into the home, the older person had the right to select the home. Some family members gave the older person this opportunity to lessen their guilt. Others wanted the older person to choose the 'right place'.

> I was afraid of her being left on her own. She insisted that she could cope on her own and that my brother and I give her another chance. She was nearly blind and she would fall or run into things. We explained to her that sooner or later she would have to move and that it was best if she did it now while she was able to select a nursing home she liked. She agreed and we saw several places before she decided on Nursing Home A (Mrs Brown 's son, never married, age - 50s; see pp 49,52).

To illustrate the diversity of situations found amongst the partial decision makers three case studies are presented below. Mr Payne and Mrs Hays represent the views and situation of those residents who made their own decision to enter into a home but left the decision of selecting the nursing home in the hands of others. Mr Hollier's story captures the situation of residents who had the decision made by others but who selected the nursing home.

Mr Payne

Mr Payne is 81 years old. His wife died eight years ago. He had never had children, and after his wife's death, lived alone. He managed with the help of home help. He had considered using Meals-on-Wheels but decided not to use them because 'the food was better at the RSL Club'. He never asked his neighbours for help because his motto is 'that you never allow others to worry about your affairs'.

He was having blackouts and was hospitalised for several weeks. 'I would pass out wherever I was'. While in hospital, the doctor suggested that he move into a nursing home. Although the doctor could not determine exactly why he was having so many blackouts (it was later discovered that he had cancer) 'he felt it was best if I did not stay on my own'. Mr Payne has an older sister but 'she is old herself' and could not really look after me'.

The doctor's advice did not upset Mr Payne. Although he had never thought about 'these places', once his wife had died, he knew 'that sooner or later he would move into one'. He was simply postponing coming 'to one'.

However, the doctor's news and his more frequent blackouts helped him decide 'once and for all'. 'I knew I was reaching the end'.

As he was too weak to search for a nursing home he asked his sister and nephew to locate 'a decent place'. His sister was an active member of the Anglican Church and knew of a 'good home'. She lodged an application on his behalf. Because Mr Payne's sister was a longstanding member of the congregation, a vacancy was made available within a few weeks. He was discharged from the hospital to the nursing home.

When asked whether he was worried about coming to a home he had never visited, he replied that he trusted his sister's judgment. He has a very close friendship with his sister. Besides, she could not have 'picked a better place'. He never thought patients would be allowed to leave the nursing home as they pleased. But 'matron explained to me that I was entitled to a taxi allowance and I was free to use the coupons as long as I told them when I was leaving the home'. Up until recently he would visit his sister and friends. He has not been 'going out' lately as his health is again beginning to restrict his movement. He does not expect to live 'that long'.

Mrs Hays

Mrs Hays is 84 years old. Her husband died 10 years ago. Although her two daughters and two sons had invited Mrs Hays to go to live with them, she decided to live alone. With some assistance from her daughters and daughter-in-laws, Mrs Hays managed her shopping and housework. 'The boys' looked after the gardening and house repairs. She was forced to think about moving into a nursing home when she found herself in hospital.

> I had a virus, Bells palsy and shingles and it left me so very ill. And they have stitched my eyelids together which they do after Bells palsy. I have very little sight. I am handicapped that way.

It was her daughter and son-in-law who first raised the subject of moving into a nursing home. Although her children are very fond of their mother, they were not in a position to care for her. Her youngest son had just recently moved interstate, while the 'other boy' was involved in a 'bad car accident'. Her youngest daughter had died from cancer while Mrs Hays was in hospital. And that left her oldest daughter.

Mrs Hays understood her childrens' dilemma, especially the burden she would have placed on her oldest daughter. She made several strong statements about moving in 'with the family'.

> I was well aware that I couldn't look after myself. And I didn't want to put myself on my family. I can't see now or just barely. I couldn't put that responsibility on my children. They have families of their own and their own lives to live. And I feel that it is not my place to intrude on their privacy. To be honest I prayed I would have died when I was in hospital. I have lived my life. My ill health came at a bad time. While I was in hospital my daughter died of cancer and my son was in a bad car accident. They did not want to put me here, and I never thought about living in a home, but what else were we to do?

After her discussion with the family and doctor, Mrs Hays 'made up my own mind'. She asked her daughter to look 'for a nice home'. After making inquiries with several directors of nursing homes, her daughter located a nursing home that had a single room and 'felt homely'. Three weeks later Mrs Hays 'jumped from the hospital to the nursing home'. She

went peacefully and willingly. Although she had 'no idea' of what to expect, she does not feel the nursing home has robbed her of any freedom. Given her health she feels 'I would be just as helpless if I was living out of one'.

Thinking back on the decision she thinks it was 'a wise one'. Her family is very important to her. She moved to lessen the burden she would have imposed upon them. With her children constantly fussing over her, she wishes to die soon so that 'they can get on with their own lives rather than worrying about me'.

Mr Hollier

Mr Hollier is 86 years old (see p 133). When his wife died, he lived on his own for three months. He has two daughters. They regularly helped him with the housework, prepared his meals on weekends and 'dropped in' after work. He was also receiving Meals-on-Wheels. But the burden of worrying about their father was disrupting 'our lives'. With the eldest daughter moving interstate and the other daughter going through a divorce, Mr Hollier's children decided that 'some other arrangement had to be found'. Seeing their father as 'an old man' and 'helpless' they decided to turn to nursing home care. He would have his meals and everyday needs attended to by nurses. They broke the news to their father.

Mr Hollier was not happy about moving to a nursing home. But under 'great pressure' from his daughters he agreed. He felt he had no choice. His wife was dead. He was living alone and his daughters 'were anxious' to see him in a home. However, he did stress that he would not

move into 'any home'. He would have to choose it. He and his daughters visited several homes. Although he did not 'like any of them' he decided to move into Nursing Home B. He chose the home because of the 'garden' and single room. But being involved in the selection of the home has not made it easier to accept his daughters' decision. The nursing home does provide him with 'plenty of blankets to keep me warm and that sort of thing'. But he can not get used to institutional living. He is 'shocked' by the lack of privacy. 'Everything is public here'.

Lessons from Residents who were Partially Involved

Elderly people do not necessarily anticipate moving into a nursing home when they can no longer manage independent living. The separation of residents into categories of being either totally involved or excluded from the decision making process fails to capture the myriad of alternatives in the spectrum. There are a number of older people who have never thought about moving into a nursing home until a crisis had forced them to think of an alternative living arrangement. Unlike the planners these people have made no contingency plans. They did not place themselves on a nursing home waiting list. However, given their preference for not wishing to be a burden on others, they made the only decision possible. Their health situation prevented them from selecting the nursing home. This selection process was left to others.

Other residents who were either counting on family support or had not thought that they would require nursing home care had others tell them that they should move into a home. Nevertheless these residents had the

good fortune of being asked to participate in the decision of selecting a home. They were fortunate in that their good health enabled them to travel and that family members gave them the opportunity to participate in the decision making process. While some of these residents may not have been happy about the prospect of living in a home, their control over where they were going to live made the decision more acceptable. The older person's involvement in the decision to enter a home can have some influence on the older person's subjective well-being. Indeed, Table 5.1 shows that of the four groups the excluded residents reported being least happy. While a number of factors can influence subjective well-being (Connor et al., 1979) a person's perception of their involvement in any decision can affect their willingness to live with their fate. As the case studies have shown, residents who made their own decision to move, like Miss Barber and Mr Hamilton, entered the nursing home with a positive attitude because this was the preferred choice of living arrangement. In contrast, residents who had others make the decision for them, like Mrs Earl, found it difficult to accept and adjust to living in a nursing home because it was not their choice. Their fate had been determined by others. Their first few months in the home were spent coming to terms with someone else's decision. The influence of the residents' involvement in the decision making process on their relationship with others and their willingness to participate in activities organised by the nursing home will be discussed in Chapter 10.

A Summary

The literature on institutional care utilisation by the aged has found that the likelihood of residence in a nursing home is higher among the very old, those without available caregivers and those in poor functional health (Wingard et al., 1987). While these predisposing factors tell us who is more likely to use nursing home care, it fails to explain the processes by which why some people turn to institutional care. Nor does it account for the considerable variations in the use of the service within particular demographic categories of people. Not all aged persons with family members are cared for at home nor can we predict with accuracy that people with similar levels of disability will automatically use nursing home care.

The findings reported in the previous three chapters suggest that the decision to use nursing home care can be partly understood within an analytic framework that recognises the importance of perceptions of situations, and how these in turn, influence actions. This model does not downplay the interactive effect between predisposing factors and individual's perceptions of their situations. Never married aged people may be more likely than their married counterparts to rely on nursing home care due to the absence of potential family care. Similarly, as chapter 3 and 4 discussed, the residents' prior living arrangement plays an important role in shaping their pathways into nursing homes. But it is people's assessment of their situation that moulds their individual line of action.

People's perceptions of managing/not-managing, entitlements and obligations and images of being an independent/dependent person play a crucial role in activating the need to seek or not seek nursing home care. Because older people are interdependent, especially with their immediate families, it is not simply their own perceptions that count. The perceptions of others, and in the case of the aged, the perceptions of their family members and health practitioners are also important determinants in explaining the use of services. Whether the older person's assessment of the situation is congruent or divergent from those of others largely explains their degree of participation in the decision making process. As Freidson has pointed out, help seeking behaviour is put into practice only when people become aware that they need help and put themselves in the hands of others.

> This is a difficult problem, for although the individual may be aware that he has some difficulty, he may not believe that it is an illness; or if he does, he may not think that it is serious enough for him to seek professional help or that it is amenable to professional ministrations as to be worth seeking help (1972:278).

Given that there are many views of managing or not managing, and that there will always be differ responses to using formal services, an important theoretical concern is the degree to which people's actions or inaction are influenced by their assessment of their situation.

CHAPTER 6

Being Chosen as a Resident : 'Am I okay'?

The previous chapters (3-5) highlighted how the decision to seek nursing home care involves a network of consultants, ranging from the intimate and informal to the more distant and formal circles. But if we are to fully understand how patients come to cross the doorsteps of nursing homes, then we must also study how directors of nursing homes select their residents.

To decide that one needs nursing home care does not mean that one will be successful in obtaining the service. The probability of successful application depends on a number of factors. For example, the organisational structure of the health care system influences the number of nursing home beds, and this in turn, affects the competition and the demand for the service. The clients ability to meet costs will influence whether they will chose to go into a public or private nursing home. In addition, residents are selected according to control mechanisms that directors use to recruit residents. Given their eligibility criteria nursing homes try to attract clients who possess certain characteristics. As a result, some people will be more successful than others in entry to a particular nursing home.

While other studies have examined how structural (or macro) factors influence the use of nursing homes (Howe and Preston, 1985; Howe 1989)[1],

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(1) These writers have shown how a number of structural factors influence the goals of nursing homes. Howe (1984) has identified four types of nursing homes depending on their funding. These are: 'private gain'-homes operated for profit and funded by Nursing Home Benefits (NHB) and patient fees (PF); 'voluntary non-profit'-these homes receive the same government benefits as private homes (NHB) but are not operated for

this chapter focuses on the micro processes by which directors of nursing home make decisions to recruit residents. The aim of the chapter is to unravel the eligibility criteria which directors use to evaluate residents and show how these influence entry into the nursing home. The influence of social structures on the nursing home industry is seen through economic incentives and pressures affecting the actions of particular individuals. Directors of nursing homes understand the conditions of their own actions and act intentionally and with reasons. The directors' perception of their own management practice is an important topic of investigation because, as chapter 10 will discuss, their objectives can vary greatly from those stated in government policies. Government policy constrains rather than determines the action of directors and others involved in the nursing home industry.

As explained in chapter 2, unstructured interviews and participant observation were used to collect data on admission rules that are generally keep hidden from the public. Reliance upon information contained in the nursing home file or completion of a written questionnaire would have not produced data on the informal rules used by directors when selecting their residents. Directors noted that the information contained in the file

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profit; 'deficit-financed' - these homes are operated by voluntary organisations and received government funding of deficits approved budgets equivalent to the NHB benefit plus PF that are limited to minimum pension contributions and cost of deficit incurred through extra paramedical services; and 'non-participating or government- homes operated by the State governments and who receive the NHB, PF which are limited to minimum pension contribution and supplement funding from State governments. The availability of beds, population characteristics and pattern of length of stay vary considerable between these four types of homes suggesting that funding affects who will be placed (Doobov and McCusker, 1986). Variations in the dependency levels of patients across states is partly the result of financial factors (Howe and Preston, 1985).

was produced to meet funding requirements. Records tell us very little about the actual decision making process and much about how things ought to be done in principle (Garfinkil, 1967).

The Myth of Uniform Patient Selection

Studies in social science and nursing literature demonstrate that despite the professional norm of universalism, patients are not treated or seen as the same. Doctors and nurses typify their clientele as either 'good' or 'problem' patients. Patients who do not cause trouble for the hospital staff and do not interrupt medical routines are evaluated as 'good'. Those who break rules are considered 'problem' patients (Lorber, 1981). Perceptions of social and moral worth also influence evaluations of patients by medical staff (Fisher and Groce, 1985). For example, doctors categorise patients inquiring about unwanted pregnancies as 'good' or 'bad' women in terms of gender-role norms, sexual behaviour and information about family interaction (Macintyre, 1977). Similarly, Gilliland and Brunton (1984) illustrate how nurses develop categories of older nursing home residents which influence their interaction with them.

These studies illustrate that before clients receive services they will go through a process of evaluation. Categorisations are based not only on the nature of the relationship between client and service provider, but also on the characteristics of the organisation and its goals. Placing patients into categories is an organisational arrangement that fosters economic efficiency and ease of work. For example, Spilerman and Litwak identify three types of patient categories which directors of nursing homes use:

> One group of patients is 'profit making' from a home's point of view, in that they require less staff time and fewer resources than the funds they bring into the home through the fixed per-diem reimbursement. A second group requires resources in an amount roughly commensurate with the funds they bring to the home; the institution 'breaks even' in providing for their needs. Finally, because of the range of patient infirmities within a single reimbursement category such as skilled nursing, there are individuals who require attention and resources in excess of the income they generate (1982:52).

Categories assist directors of nursing homes to select residents whose needs can be meet by the institution. Although these studies identify how categories of patients are constructed, less attention is paid to the factors that influence the directors' decision regarding 'who gets in'.

All organisations have goals and ideologies governing work and client service. Although formal goals are important, there is often a discrepancy between the way an organisation announces its services and the way it actually conducts its business. On the one hand, all nursing homes could claim that they are providing institutional services to the most disabled and needy members of the community. On the other hand, a variety of factors such as particular organisational goals, formal policies, limited resources and typifications of patients also influence the choice of a successful applicant. Acceptance of more disabled or needy applicants is not invariable.

The Referral Process : Implications for Selecting Residents

Nursing homes, like other organisations, can not be studied as unified, closed systems. Rather, they interact with other health and community agencies. In this context, nursing homes can be conceptualised as part of an open system receiving inputs from the environment, processing

them in some way and then announcing its goals to the community (Maykovick, 1980). This process is highlighted by the observation that nursing homes not only receive patients but also discharge patients to other institutions or the community. Agencies in the system are interdependent. Nursing home residents who require frequent or intense medical care need to be moved to a hospital bed, while hospital patients who need nursing or convalescent care may to be discharged to a long-term nursing home. Because other agencies will be resistant to accepting referrals of potentially disruptive patients, referral networks are carefully selected. Collaboration between systems are negotiated on the basis that the arrangement is serving the interest of all parties and producing the desired benefits. Once patterns of recruitment are established, sponsorship becomes a two sided process. For the relationship to continue, each party is obligated to fulfill the needs of the others.

While the directors were working within different organisation and funding structures, all eight directors spoke about the importance of establishing a referral network which enables them to pursue both their organisational and individual goals within the constraints of government policies. This sets the parameters for the types of clients who become potential candidates. A further typification process occurs when a director selects residents from the pool of applicants. The decision of 'who to select' is contingent not only on external pressures but also on internal management, such as matching the characteristics and resources of the vacant bed with the attributes of the applicant.

Clients are brought together with the nursing home director in several ways. They may contact the nursing home themselves, have family

members or friends make contact for them, or be referred by health professionals. This suggests that patient selection could vary between the lay and professional referral system. Table 6.1 shows that differences in the source of client referral exist between the different homes. Direct contact with family members or the older persons themselves account for over four-fifths of all admissions in Nursing Homes A,B, C and D. These homes rely on a lay referral system and did not identify themselves as belonging to a professional referral network. Nursing home A and B are voluntary homes run by a religious organisation (Roman Catholic church). Both homes have on-site hostels and draw most of their applicants from this population. Gray and Lazarus (1987) have found these kinds of multi-stage complexes have a low participation rate in regionalised nursing home placement list programmes. In contrast, Nursing Home C is a private nursing home and Nursing Home D is a charitable home.

The directors of Nursing Homes E, F, G and H rely most upon referrals from health professionals, usually social workers or physicians. These homes can be viewed as 'dependent practices' (Freidson, 1972), where the organisation does not in and of itself attract its own clientele, but relies on referrals from other agencies. When the directors of these homes were asked to specity who were members of their referral team, the names of specific physicians and social workers were given. Although they do accept referrals from lay people, these account for a very small percentage of the admission. Less than one quarter of their admission was from such sources. Unlike the lay referral system where clients select their services, in a professional referral system clients are transmitted from one agency to another. The colleague network revolves around being a member of a

Table 6.1 Percentage of patients referred by either a lay or professional network by nursing home *(a)*

Nursing Home	Percentage of Residents Referred by		Total
	Lay Network %	Professional Network %	
Nursing Home A	81	19	100% (37)
Nursing Home B	87	13	100% (30)
Nursing Home C	80	20	100% (15)
Nursing Home D	88	12	100% (34)
Nursing Home E	6	94	100% (16)
Nursing Home F	21	79	100% (39)
Nursing Home G	29	71	100% (17)
Nursing Home H	9	91	100% (33)

(a) The data is based on all residents admitted to the nursing homes between the 1st of January to the 31st of December 1982. For each admission in that year, the director was asked to identify the person who referred the client to the home. This is not the person who signed the Nursing Home 5 Form but the individual who first negotiated the admission with the director.

fraternity in which clients, technological resources and manpower skills are exchanged. Three of these homes are private nursing homes and one is voluntary home run by religious organisation (Church of England).

Differences in referral networks between nursing homes can be partly explained by funding. Under the funding system of the early 1980s private nursing homes were dependent on the ordinary/extensive care classification system to secure such funding. For the home to operate at a profit, 75 per cent of the residents must meet the extensive care classification (Director of Nursing Home G). As a high proportion of the residents recruited are high care patients, referrals from health professionals

or assessment teams are seen as convenient. This is because patients have already been assessed and this reduces the time required by the director to evaluate and maintain up-to-date information. Voluntary nursing homes under the deficit financed system, however, were given funding on the basis of their actual costs; the better the directors were at submission writing and negotiating, the more funds they obtained. Lay referral sources give the director more flexibility in finding clients, which allows the nursing home to achieve a mix of low and high care patients and for the director to select the most 'appropriate' admission.

Nursing Homes which Rely on Lay Referral Networks

As Table 6.1 shows, four homes (A,B,C, and D) can be classified as relying on lay people, such as family members or clergy, to locate clients. None of these nursing homes advertise in the media. They have over the years built a reputation with the residents in their local community. The nursing homes are seen as facilities which care for old people.

Nursing Home A and B

Nursing Home A and B are voluntary nursing homes run by the Roman Catholic Church. They are discussed together because they are attached to separate hostels. This organisational structure influences how nursing home residents are selected. Few of the residents living in the nursing home are admitted directly from the community or from another institution. This admission policy is the result of management promising clients in the hostel a place in the nursing home. Over 90 per cent of the residents in the nursing home were formerly living in the hostel. Only when

a vacancy in the nursing home can not be filled by clients in the hostel will the director seek applicants from outside sources. Thus, to understand how residents come to live at these nursing homes, we must first investigate how they were selected for admission to the hostel.

The directors of both homes nominated relatives as the most important source of referral for hostel care. Family members contact the nursing home because someone in the community has recommended the establishment. It is not uncommon for other family members or friends to have lived at the home. 'There are many examples where three or four sisters have been cared for by us'. The other callers are older people themselves and professional referrals, usually a social worker. Preference is given to applicants who live in the community and recommended by a known source. Because both directors see their nursing homes as religious institutions, money is not an important criteria used to select patients. The government subsidy and the applicant's pension cover the cost. Rather, the selection method is based on the director's assessment of the congruency between the characteristics of the applicant and the type of patient required to fill the vacant bed. Callers are screened on the basis of their medical and social characteristics. An interview with the older person and their next-of-kin is arranged before the applicant's name is placed on the waiting list for entering the hostel. The interview assessment consists of a panel of senior staff members. The purpose of the interview is to assess whether the person is to assess whether the person 'passes our test to live in hostel circumstances'.

Both homes conduct similar admission assessments to determine applicant eligibility for hostel care. The first item on the test is health status.

Staff members try to determine whether or not the aged person is in good physical health. The hostel offers limited nursing services and its residents are expected to manage independent living. Several health tests are conducted. Staff members expressed a concern about the validity of medical reports submitted by the client's physicians. To cross check the medical report, residents are examined by a physician chosen by the director.

> Vic: Do you give your clients a medical examination before they are admitted?
> Director: Oh yes. We always have our own doctor do a medical report.
> Vic: Why?
> Director: Well it is possible that because of the pressure put on the physician by relatives to get the old person into the hostel that he may not give you all the facts.
> Vic: Do you often get discrepancies between the medical reports?
> Director: It does happen. For example, we had an application where the person was a diabetic who was on insulin. The doctor did not put that information on his report. But our doctor found out that the person had insulin injection twice a day. Well that barred her from the hostel because she required supervision to administer her injections.
> Vic: Do you think her doctor knew this?
> Director: Most probably. This is why we have to check (Director of Nursing Home B).

In addition to this medical examination, staff members assess the older person's physical ability by taking them 'on a tour'.

> We walk them around. We can soon tell if somebody can walk the whole tour. If they can't, then we know that the person will have difficulty going to the dining room three times a day. This tells us that she should be applying for nursing home care because she is not fit for hostel living (Director of Nursing Home B).

At the same time, the patient's mental alertness is under examination. Questions relating to present and past events are specifically included in the conversation to 'see whether the person is vague and confused'. During the interview, staff members take notes and compare their results. The health criteria used are very specific: 'if they can make the distance from their room to the dining room, if they can shower themselves, if they can keep a tidy room and are mentally alert, they pass the medical report'. The medical report thus serves as a screening device to avoid undue burdens on staff rather than to ensure that the most needy individuals are served.

But meeting the director's health criteria does not guarantee that the applicant will become a candidate for admission. A person's social attributes are also reviewed and matched with the requirements of the organisation. Several social categories were outlined by the staff members.

The nursing homes are run by a religious organisation and preference is given to Roman Catholics. The director of Nursing Home A explains that religious affiliation can make a difference in whether or not the person will be happy living in the home.

> I think it is very important for the person to be of the same faith as the other residents because you can not expect them to fully adjust. I can think of one lady that is with us at the moment and everything seemed to go alright at the interview. At the interview, she told us she was Roman Catholic. But the staff noticed that she was not mixing well with the other residents. I visited her and although I did not get much information on the first day, after several more visits, I finally got the story. She was not Catholic and it upset her very much to see all the symbols of our religion around the place. She felt she was not getting on with the other residents because they were all Catholics. She felt different.

Whether the older person wants to move to the hostel is another selection criteria. Separate interviews with the older person and the next-of-kin are arranged to detect if different 'stories' between the two parties exist. The older person's feelings about moving are important because 'the older person will never fully adjust if they do not want to be here'. These clients are seen as potential trouble. They are considered to be reluctant to participate in the recreational activities, integrate with other residents or cooperate with nurses. 'These are the whingers'.

Another benchmark is whether the staff can count on the applicant's family to assist them in caring for the aged person. The staff determine whether the family will provide services such as visiting, taking their aged kin out for walks, and doing their laundry. If family members are judged to be dumping their responsibility to the hostel, these applicants are viewed unfavourably because they will be high users of the limited staff resources allocated to hostel care.

> Vic: How do you tell when the family is trying to get rid of their aged relative?
> Director: It is part of our assessment to conduct separate interviews with the old person and her family. And over the years you have heard so many stories that you can usually tell whether it is a dump case.
> Vic: Can you give me an example?
> Director: A son brought his mother with his wife. His mother was being treated for a leg ulcer and they took her out of the hospital for the day, probably because it was time to discharge her. So that alerted me to the fact that they were urgently trying to find a place for her to be transferred. But that is alright because so many other families find themselves in similar situations. It was what they said about their mother that made us suspicious of how they got on with each other. Their stories told us that there was a lot of water under the bridge between the old lady and her daughter-in-law. After a while, it became obvious that they were trying to get rid of her and we were their first stop.

Thus, whether or not an application will be successful depends on the client (1) being referred from a known source; (2) passing the health criteria of independent living; (3) being a Roman Catholic who wants to move; and (4) has a supportive family. If the applicants meet these requirements, the chances of their names placed on a waiting list is greater than if they lack these attributes. However, this does not guarantee immediate placement. Clients are not selected on the basis of when the application was lodged. A list of short and long term placement is constructed. From this list, the director decides which person best fits into the vacant bed. For instance, if the person will be sharing with another person or living next door to certain types of people, personality becomes an important selection factor.

Because the nursing home is an extension of the hostel care, the director in collaboration with the nursing home's physician, decide when it is necessary to transfer patients to the nursing home. Family members are consulted about the move but, as they have entrusted the care of their aged relative to the director of nursing home, they seldom oppose the staff's decision.

The decision to transfer patients to the nursing home is based on a physical assessment of whether the resident is coping with independent living in the hostel. Hostel residents who become incontinent, mentally confused or are dependent on others to assist them with daily activities are at risk for placement into a nursing home. Because of the stigma attached to entering the nursing home, hostel residents rarely request to be moved. They 'go to great trouble' to hide signs of poor health. For this reason, staff members conduct regular 'rounds' to identify potential users of nursing home care.

> Very few residents will admit that they are not coping with independent living. They think that if they go to the nursing home they will die. So we are forced to do
> our own investigation. For instance, just recently I requested that this lady be transferred. I did my rounds and noticed that she had difficulty going to the dining room. Her friends were bringing food to her room. I also found out that they were helping her with cleaning the room -- this was okay but not being able to go to the dining room was the yardstick that sent her to the nursing home (Director of Nursing Home B).

Nursing Home C and D

Nursing Home C and D have different organisational structures - the former is a privately owned home run for profit while the latter is a voluntary home run by the Church of England - but both homes rely mostly on referrals from lay sources. Relatives are their major source of referrals. Children act on behalf of aged relatives and often without the consent of the aged person. Families are looking for an immediate placement.

> Quite often you will get a call that mum or dad is living at home, and they will tell you to return their call at work and not to ring at home. This is because they do not want their parents to know that they are thinking of putting them in a nursing home. They have not told them yet (Director of Nursing Home C).

Referrals from social workers are not common. Although both nursing homes have adopted a policy not to recruit clients from social workers, they offer different explanations for their decisions.

Nursing Home C is a private establishment whose aim is to run a profit making business. Social workers are seen to represent clients who cannot meet the fees.

> We do get calls from them but we have got a reputation of never being able to accept them. Social workers will only refer clients to us if they can pay the admission fee. They have a secret list, and over the years, they know what your admission criteria are. For us, it has to be someone who can afford our fees (Director of Nursing Home C).

It is because the nursing home is searching for clients who can afford the admission fees that community referrals are preferred. This market requires a pool of clients who can purchase the service.

All callers are 'indiscriminately' sent information about fees and an application form. This procedure screens out people who require an immediate placement or find the admission fees too expensive. Once the application is returned, the director interviews the person who completed the forms, usually a family member. Information about the aged person's health, living arrangement, and reasons for the application are collected. This 'data' allows staff members to decide whether the applicant meets the eligibility criteria.

> The interview helps me to visualise the person in my mind. I get to know them before they ever come in. I know what the family problems are, why they are not coping, what their mental and physical state is like and something about the family (Director of Nursing Home C).

If the applicant can afford the fees and wait for a vacancy, the director then assesses the family situation. Will the family provide support once the aged relative is admitted into the nursing home? As recreational programmes are organised around family participation, availability of family is an important factor in the staff's decision of who they select. This provides another reason to discourage referrals from social workers. The

director sees social worker clients as having different support networks than people referred by family members. She explains:

> Director: If you get a referral from a family, well you can make a good guess that the older person is either living with them or receiving support from them. The people admitted from social workers are invariably getting no support or minimal support from their family. Of course, there will always be exceptions and you will get a couple of admissions from social workers where there is a caring family. But the general experience is that often they lack caring families.
> Vic: Why are caring families important?
> Director: The public does not seem to realise that we can only provide so much support to the old people. The most important support will always come from families. A good nursing home is one that has the family on board. They are the other half of the staff. Without them, life is miserable for the residents and more work and time is requested from the staff.
> Families play an equally important role after the admission. If they continue to provide support to the old person, then this can make the <u>difference</u> between someone who comes in rejecting or accepting their surroundings (Director of Nursing Home C).

Nursing Home D is also not linked to a social work referral. The director gave a different explanation for her decision not to be a member of a social work network. As a voluntary institution, Nursing Home D was established to meet the needs of the local community, and more specifically, members of the Church of England. Over three-quarters of the residents are from this religious background. Thus, the nursing home relies primarily upon community referrals. This reliance upon lay referral enables the director to control client eligibility. Unless the applicant is both a member of the local community and a member of the Church of England, chances of admission are low. Social worker referrals are restricted to clients who live in the district.

The timing of admission depends on the priority needs of the nursing home. The director selects that applicant on the waiting list who best matches the prerequisites of the vacant bed. The following example highlights how the director of Nursing Home C makes this decision.

> It is based on my assessment. When I get a free bed, the first thing I do is decide whether there is anyone already in the nursing home who should move into that bed. After that, because I have been talking with the families every three or four weeks, I have a pretty accurate picture of what the patient is like. I can use my notes to determine what she can or can not do. So I offer the bed to someone who is going to fit into that situation as best as possible.

Waiting lists do not guarantee fairness in selection. Clients are chosen not according to date of lodgement but to factors related to the organisational needs of the nursing home. For example, all of the directors interviewed allocate a certain percentage of their beds for 'social admission'; patients who display a high degree of independence with daily living activities. Directors of nursing homes do not select social admissions specifically for profit making reasons. Directors of nursing homes seek out low dependency patients in order to reduce the workload of staff and make their work more manageable. Often these patients occupy areas of the nursing home (eg., second floor) that would be inconvenient for less mobile patients. Vacancies in these quarters require that the director searches for a mobile client.

> We put people's names on a waiting list but because of our situation (two storey home), if I had a vacancy upstairs and I had a mobile person on the waiting list, then she would probably jump the list even though her name may appear behind other

> applicants. And she would probably get in before a bed patient, although in a sense that person would have less of a medical need (Director of Nursing Home C).

Nursing Homes which Rely on Professional Referral Networks

This section examines the way in which some nursing homes collaborate with a professional referral network in recruiting and selecting patients. Table 6.1 shows that four of the eight nursing homes (Nursing Homes E,F,G,H) recruited most of their applicants from referrals by physicians or social workers.

Nursing Home E

Nursing Home E is a voluntary home run by a charitable organisation and, because it admits only psychogeriatric patients, it will be discussed separately from the other homes. The home has established a strong link with the hospital located across the road. This association ensures that 'outside' referrals from other hospitals or the community are seldom accepted. When a vacancy arises, the director contacts the social worker at the local hospital. The social worker recommends a list of potential clients.

The decision to seek nursing home care seldom includes the aged person. These patients are often long term residents of other institutions. With few options open to them once the administration of these facilities decides that the time has arrived for a transfer, they leave the details of the move to health professionals. Moreover, as many of these residents have no contact with their kin, they do not have family members to act on their behalf.

> Out of the 34 patients, I would say that half of them have no family members who get in touch, 10 patients have family members who visit only once or twice a year, and only 6 patients have supportive children or sisters who regularly visit and take them home on weekends or special holidays. By the time they arrive to me, they have been disowned by their children. Their family exists only in our file or in the older person's past memories (Director of Nursing Home E).

Hospital authorities are under pressure to discharge patients when treatment has been completed and the older person has few options available. Without a residence to return to, or family members willing to look after them, the relocation decision is left in the hands of the hospital authorities. The aged person is a third party who does not worry about the details of the admission process. Social workers negotiate on their behalf for the 'best deal'.

With an increase in the number of aged persons, and their use of medical services, the 'back up' of geriatric patients in acute hospital beds has become a salient health care issue (Rubin and Davies, 1975). Under administrative pressure to free the 'blocked bed', social workers in hospitals are searching, in a competitive market, for an immediate transfer to a nursing home. Unlike family members, social workers do not have the emotional need to go through a ceremonial visit with the aged to justify their decision.

The admission criteria to Nursing Home E appears to be straightforward. Clients must have a psychiatric disorder and be a former patient of the local hospital. However, not all psychiatric patients at the hospital are considered to be candidates for placement. Physically impaired patients are not accepted because the nursing home does not have the

financial and staff resources to care for them, nor have staff members designed appropriate recreational and therapy programs. Such patients are seen as 'not benefiting' from the activities.

> We always try to recruit someone who can take advantage of our activities. These people are often patients who are mentally handicapped but can still take part in our recreational programs. Someone who is physically disabled could not use our services. It would be difficult for them to go on our bus trips or participate in other activities (Director of Nursing Home E).

Thus, whether clients are recommended and accepted depends on whether the client meets the criteria negotiated between the social worker and director.

No waiting list is kept by the director. As a member of the hospital referral network, there is never a shortage of patients. When a vacancy occurs, usually because a resident has died, the director contacts the hospital social worker and they jointly select a new resident.

Nursing Homes F, G, H

Nursing Homes F, G and H are examples of private organisations that recruit clients mostly through social workers and general practitioners. The directors of Nursing Home F and G have entered into agreements with social workers at several hospitals because they can coordinate resources with the hospital to achieve mutually desired goals. They prefer to rely on referral from hospitals because clients are given a physical assessment prior to admission. As a result less nursing staff time and resources are used to assess clients prior to admission. Clients already have been counselled about

the decision to move and staff members do not have to mediate between the aged person and the family. Social workers have performed this role.

The directors see this inter-organisational relationship as meeting the needs of both the nursing home and the other parties. For example, as the director of Nursing Home G explains, patients are swapped from the nursing home to the hospital to 'get around' losing benefits for holding unoccupied beds when the resident is transferred elsewhere for acute care.

> Director: We will accept referrals from social workers at --- and --- hospital. We rarely accept patients from other hospitals or the community.
> Vic: Why?
> Director: I have over the years worked out an understanding with these social workers. I accept their convalescent patients, and in return, when I have to transfer one of my patients to an acute hospital, they will send me one of their patients to hold the bed until our patient is discharged back to us.

Nursing Home H is a private nursing home which relies on general practitioners to refer patients. But not all physicians in the local community are accepted as partners. The director selects physicians who have a geriatric clientele and who understand the goals of the nursing home.

Two types of aged clients were identified by this director. The first category includes older people who are already in an institution and require long term care. They will require more extensive care and make heavy demands on the nursing staff. The second category of clients are frail persons in the community who cannot rely on family support to remain at home. If carefully selected to include a mix of people varying in their disability level, these people can be balanced to take up resources while still bring in a profit. As the home's primary goal is to 'make a profit', the

clients from the community are preferred. The nursing home also prefers clients without family ties. Over three quarters of the residents living at this home were without families.

> Most of the people here do not have family. They seldom get visitors or have people bring them special foods, cigarettes, take them out on special holidays or assist us with the laundry (Director of Nursing Home H).

Not under the scrutiny of family, the director can provide minimal services, limit cost to ensure a profit margin and not worry about accountability to family members regarding quality of care. The director collaborates with physicians because she is searching for a pool of clients that will allow the home to provide care within the capacity of the available resources and make a profit. Physicians come across many patients who fall into the category of 'profit-makers'. Doctors are thus seen as the gatekeepers between the older person and the nursing home. Doctors in the referral network provide medical services to residents living at the nursing home.

Conclusion

Entrance into a nursing home is a selective process. A person's success of being admitted into a particular home is partly influenced by whether the director does business with the person who is organising the admission. Depending on who is referring the older person, some people are more likely than others to be considered as clients.

The analysis so far has traced the decision making process in terms of people recognising the need for formal care, to someone making the decision to seek nursing home care, and being placed into a home. A common thread

running across this process is that often these negoitations are being conducted without the involvement of the older person.

The selection of a home can represent an opportunity for an older person to participate in the decision making process. Family members and directors have many reasons, however, to avoid consultation with the older person. Family members also find it difficult to discuss the topic with the aged person, and as a result, collaborate with others to make the decision on behalf of their relative. A coalition between family members and health professionals is set in motion even before the person enters the nursing home. This exclusion process continues when people are searching for a home. At the administrative level, directors rely on referrals from either health professionals or relatives. By relying on referral networks that do not include the aged, directors are under no obligation to solicit direct contact with the older person. Not surprisingly, the aged are seen by directors to be the objects of their work (eg., management and control) rather than as clients (Murphy, 1988).

Recently, a number of government policies, including the introduction of geriatric assessment teams, have been introduced to control placement into nursing homes. The aim of these policies is to restructure the utilisation patterns of nursing homes. This has become a significant political issue (Howe, 1989). Chapter 10 will discuss the reasons why such changes may not be welcomed by the nursing home industry and the effects they may have on the quality of life of residents.

CHAPTER 7

Visitors to nursing homes: few or many?

Having examined the factors that pull the elderly into nursing homes, and the issues associated with the decision making process, the next two chapters examine different aspects of the social interaction of older people after they enter nursing homes. As the majority of residents will stay for the remainder of their lives in a nursing home, understanding the types of contact the older person has with family and friends is an important topic associated with research on institutional care.

The social support networks of older Australians living in nursing homes has been an uncharted area in research. This and the following chapter shed new light on the issue of isolation of older people living apart from family and friends. This chapter reviews the literature on the social interaction of older people in nursing homes and provides a description of visiting patterns. Chapter 8 looks in more detail at the processes and determinants of these visiting patterns firstly, by using quantitative information, examining the interrelationship between visits and the characteristics of residents, visitors and nursing home; and secondly, by using qualitative information, demonstrating the processess which explain these levels of interaction and their human consequences and meanings.

The Impact of Institutionalisation on Visiting Patterns

Institutional living can change in many ways the older person's contact with the outside world. Visiting rules and regulations make it much more difficult for the older person to maintain external interpersonal

relationships. The older person often has to wait until others decide to visit. Group living can create a barrier to what people can say and how they will act towards one another given the presence of strangers.

Contact with family and friends still remains important to residents. Family ties are valued in themselves and provide important links with earlier life experiences (Marshall, 1986). Through interaction with family and friends, residents can retain their former identity and familiar contact with the outside world. It is not surprising that contact with family is an important predictor of psychosocial well being of nursing home residents (Greene and Monahan, 1982). When families continue to be involved, the quality of care appears to be better. Nursing home residents whose families visit them regularly receive better treatment from staff, feel less alone and have more personalised living quarters (Dobrof, 1974). The presence of visitors has the additional benefit of decreasing the overall institutional atmosphere of the nursing home.

With more lesiure time available and fewer chores to undertake since moving to the nursing home, receiving visitors is a central focus of the residents' life. Residents notice and remember who receives visitors. Those with many and frequent visitors are considered fortunate.

> I really can not complain. Someone in my family comes and sees me everyday. Some of the people here never get any visitors. And it is not because they do not have any children. They do. But they do not come. I am very fortunate (Mrs Greene, 92 years old, widowed; pp 72,80,82,92).

The social science literature reports that nursing homes can have either a negative or positive influence on the relationship between residents and their families. Some gerontologists,heavily influenced by Goffman's (1961) analysis of total institutions, describe the iatrogenic aspects of life in a

nursing home. Nursing homes are seen to exist independently from society. The physical design of nursing homes often creates an impersonal environment which inhibits personal interaction (Gottesman and Bourestom, 1974). Images of soiled or demented patients, intolerable smells, and abusive nurses can keep visitors away. The most negative image of institutionalisation is its association with the withdrawal of family support. It is frequently assumed that those in nursing homes have been abandoned and forgotten by their families and friends (Bennett, 1980).

A more positive view of nursing homes is also presented in the gerontological literature. Recent studies of institutionalisation have raised questions about previous assumptions regarding the negative effects of admission into a nursing home (Kahana et al., 1985). The portrait of nursing homes as dehumanising and depersonalising is contrasted with themes of increased social interaction with the outside world and, in some cases, improvements in lifestyle and levels of satisfaction (Myles, 1980). These studies are beginning to dispel the myth that elderly persons are dumped into nursing homes and forgotten by society (Dobrof, 1974; York and Calsyn, 1977). As the stories of families revealed (see chapter 3), they are not always in a position to care for their ageing relatives, either because of limited financial and housing resources, or because their ability to continue providing care is made difficult by the more demanding needs of the older relative. It is only when informal support has been exhausted that many family members turn to formal agencies for residential care (Shuttlesworth et al., 1982).

Family members, however, do not necessarily withdraw from the lives of their aged relative after institutionalisation. In a comparison of social interaction patterns before and after placement, Kahana et al. (1985)

reported that there were no significant changes in either the number of people with whom residents were close to or with whom they interacted. Family members continue to play important roles by visiting and providing personalised services to the aged relative (Litwak, 1985). Family ties can even improve because placement eases the demands and strains placed by an elderly relative on her family (Smith and Bengtson, 1979).

The opportunity for residents to receive visitors, however, can depend on several factors. First, people must be available, and the more there are of them, the greater the likelihood that the older person will interact with someone. Research on the family of older people living in the community suggests that marital status affects the size of the networks (Brubaker, 1983; Mugford and Kendig, 1986). Married people have larger networks than people who are separated or divorced, widowed or never married (Kahn and Antonucci, 1983) and potentially have more family members or friends who can visit them. However, interaction often depends on residential propinquity; that is, how close people live to one another. Since long distances require greater time and expense for the potential visitor, family members and friends who live near to the nursing home could visit more frequently than those who live further away. Indeed, several studies have found distance from relatives is an important predictor of frequency of visitation (Greene and Monahan, 1982; Hook et al., 1982). Greene and Monahan estimate that 'a 10 mile increase in distance is associated with a decline in visitation frequency of approximately .5 visits per week' (1982:423).

Studies have shown that the patient's health, daily functioning level, and behaviour can be partly explained by the effects of 'total institutions' (Borup, 1982; Goffman, 1961). Formal rules which control the life-styles

of residents can also constrain how people interact with one another (Clough, 1981). Nursing homes which do not include families and friends in recreational activities, and have limiting visiting hours, receive visitors less frequently than nursing homes who include families (Montgomery, 1982). This suggests that whether visitors feel welcome can increase their interaction.

The length of time patients have been in the nursing home may affect the frequency of visits. For instance, Greene and Monahan (1982) found that with each month in residence there was an associated .015 decline in visiting per week. Recently admitted residents may initially receive frequent visits from relatives who are concerned about the patient adjusting to the new environment, but with the passage of time, these contacts may revert to old patterns. Also one cannot ignore the possibility that, as time passes, some relatives may forget the older person, even though initial contact may have been extensive.

Other factors identified in the literature as influencing interaction are the attributes of the person being visited and of the visitor (Hook et al., 1982). There are differences in the nature of social ties between men and women. Women in the community have larger networks (Kahn and Antonucci, 1983), report providing and receiving more support from their children, and are more concerned and develop more expressive relationships than men (Mugford and Kendig, 1986). They are more likely to include both family and friends in their networks and have more close relationships or confidants than men (Chiriboga, 1982; Kendig et al., 1988). Such differences are explained by women having better interpersonal skills and developing more affectionate relationships with family members and children than men (Troll et al., 1979).

The degree of physical or mental disability can influence visiting (Greene and Monahan, 1982). The health status of residents not only affects their ability to communicate, but also how others perceive them as recipients of affection and interaction. For example, adult children may discourage their own children from visiting their mentally handicapped parent because of the stigma associated with mental illness.Greater disability of the older person possibly requires more obligatory motivation relative to affection or mutuality; a basis for interaction more likely to be forthcoming from children and spouses than other family or friends (Kendig, 1986).

The attributes of the visitor must also be taken into account when trying to untangle the factors associated with visiting patterns. People's health may create a barrier to travel to the nursing home - a difficulty more likely to be experienced by spouses, siblings and other aged peers. Consideration must also be given to other competing obligations that may inhibit or enhance visiting. For instance, with more middle aged women entering the labour force and working until retirement, there may be fewer daughters and daughters-in-law available for daily interaction with older people (Trol et al., 1979). Finally, the amount of interaction can also be influenced by the quality of the relationship built up over the years. The above discussion suggests that the attributes of the resident, of the visitor, the nature of the relationship between the resident and visitor, and the characteristic of the nursing home can determine visiting patterns. The influence of these factors on visiting will be studied in detail in chapter 8.

Nursing Homes: Places without Visitors?

Overseas results show that the institutionalised aged generally are not forgotten or abandoned by their families or friends(for a review see Kahana

et al., 1985). The present study produced similar findings. Over three quarters of the present respondents, report having had visits, letters or telephone calls from people living in the community during the week prior to the interview. Table 7.1 shows that only 17 percent of residents with children and less than one third of residents without children lacked external contact with a child, another relative or friend.

Visits are the most common ways in which people maintain contact with aged relatives living in nursing homes. Less than one-third of theresidents reported receiving a letter or telephone call in the last week. Several explanations for this are suggested. People are less likely to exchange letters, except on special occasions, if they live in the same city; over three quarters of the residents' family members and friends were living in Sydney. Telephone contact is partly dependent on the availability of a telephone. Few residents have their own telephone (three out of 182 residents). In addition, some directors discourage residents from having a private telephone because it can interfere with nursing home practices. One of the directors explained:

> It's a little bit restricting because once a person has paid for a telephone installation, which is about one hundred and seventy-five dollars, it really means that I have to think very seriously before I move that person out of that room if the person requires a bed that has more resources attached to it (Director of Nursing Home C).

The resident's health (visual and hearing) can also limit contact via the telephone or letters. However, for most of the residents in this sample, health can not account for why the telephone was not used more frequently. Health assessments by the directors revealed that 89 per cent of the residents

Table 7.1 Percent of residents with children who have at least one of their children, another relative or friend visit, write or telephone them and residents without children who have one of their relatives or friends visit, write or telephone them during the week prior to the interview [a]

	With children (121) %	Without children (61) %
Saw a child	69	-
Received a call or letter from a child	16	-
Saw another relative or friend	57	62
Received a call or letter from another relative or friend	27	10
No contact	17	31

a This data is derived from the socio-health survey of 182 patients (see chapter 2).

did not have a speech or hearing impairment. Less than two-thirds of the residents were judged by the directors as being capable of using the telephone. It was administrative practices which prevented residents from communicating more frequently on the telephone.

The majority of residents, however, did have relatives or friends visit them. Table 7.1 illustrates that 69 percent of residents with children had at least one offspring visit during the week prior to the interview. While children, next to a spouse, are the most reliable form of ongoing support to

vulnerable older people (Kendig, 1986), more than half of the residents with children also reported seeing another relative during that week. This suggests that grandchildren, siblings, nieces and nephews can play equally important roles in providing expressive support to old people.

Although childless older people may be at greater risk of being without support, Table 7.1 suggests that they generally are not forgotten by others once admitted into a nursing home. Sixty-four percent of these respondents report receiving at least one visit from a relative or friend, although they were twice as likely as residents with children not to have anyone contact them. However, they were more likely than residents with children to have received a visit from a sibling or other relative the week before the interview. This suggests an interesting pattern of responsibility taking by other relatives and friends when a person is known not to have children. It also probably echoes past social contact.

The Social Networks of Residents

Although the results thus far show that nursing homes are not ghost towns, inhabited only by residents and staff, it does not identify nor explain which members of the older person's network are more likely to visit. One way to address this question is to develop a complete picture of the significant individuals in the older person's network, and then examine who actually visits the older person.

A social network matrix, similar to that developed by the Ageing and the Family Project (Kendig, 1986), was produced by asking each respondent in the in-depth study to list all of their immediate surviving family (spouse, children, grandchildren and siblings). In addition, the respondents were asked to provide the names of other family members and friends whom they

felt to be part of their network circle. All of these people are seen as potential visitors. Each respondent was then asked to state how often they saw these people on a six point scale from daily to not at all in the last two years.

Table 7.2 presents a summary of the characteristics of the 1011 potential visitors in the residents' network. There are few family members or friends who are daily visitors to the nursing home; only one per cent of the network members of residents were daily visitors. In contrast, 16 per cent of older people living in the community report daily contact with family members (ACOTA, 1985). There are several reasons which can account for why older people living in nursing homes have less frequent daily contact with family members. The older person in the community is often able to visit as well as be visited. Nursing home residents often have to wait for others to visit them because of rules restricting their movement outside of the nursing home or their poor health preventing them for leaving the premises. As chapter 8 will show the decision to institutionalise an aged parent can create tension in the relationship which may result in relatives visiting less often. Most family members and friends, however, do visit their aged relatives. Only 19 per cent of network members had not seen their aged relative or friend in the last two years.

The profile of the network members indicates that in terms of residential location and employment a large number of people are potentially available to visit. More than three-quarters of the people nominated in the older person's network lived in Sydney. The location of the nursing home to relatives is important in determining how frequently people visit given the increasing costs of transportation and travel inconveniences. Most people in the residents' networks lived within a 15 mile radius of the nursing home.

Table 7.2 Summary of the Characteristics of Potential Visitors

Variable	%
Gender	
Female	55
Male	45
Age	
Under 13	9
Teens	7
'20	12
'30	11
'40	14
'50	14
'60	15
70's and over	18
Marital Status	
Never Married	28
Widowed	12
Married	56
Divorced/Separated	4
Travel distance to nursing home	
Same neighbourhood	8
Within 5 to 10 miles	29
Within 11 to 15 miles	26
In Sydney, over 16 miles	14
New South Wales	12
Interstate	9
Overseas	3
Employment	
Full-time	33
Part-time	7
Not working	60
Frequency of Visit	
Daily	1
Semiweekly	4
Weekly	10
Semimonthly	18
Monthly	26
Yearly	23
Not in the last two years	19
TOTAL	100%
	(1011)

In addition to being geographically nearby, a number of people were also not restricted by employment obligations. However, a person's age or other competing family obligations can reduce their availability to visit regularly. Seventeen per cent of the potential visitors were under the age of twenty.Their presence in school during the day and the visiting hour policies of nursing homes can make it difficult for young people to visit during the week. Older relatives, because of their health, may also find it difficult to regularly travel to the nursing home. Eighteen per cent of the residents' family and friends were 70 years of age and over. Traveling between five to fifteen miles on public transportation may also be expensive for many older people to manage on a regular basis. Finally, as chapter 3 showed many adult children are married and providing support to other members of their own families. This can pose a barrier to maintaining daily contact with an aged parent who is depend on others to visit them.

The network size of residents varies by marital status (see Table 7.3). The average social network contains nearly 12 people, and almost half contain eight to 13 people. As reported elsewhere, socio-demographic status influences support networks: 'to be born female or male influences people's abilities to activate social support 65 years later. To have children potentially provides both genders with ties grounded in filial obligation and attachment' (Mugford and Kendig, 1986:59). This study, unlike the community survey of Mugford and Kendig, found no significant gender differences in the resident's social network size ($t = -.57$; $df = 88$; $p > .56$). However, Table 7.3 shows that noticeable differences according to a person's marital status were observed ($F= 6.7$; $p < .001$).

Table 7.3 Breakdown of network size by marital status of resident (N = 90).

Marital status	Network size
Single	6.36 (SD = 3.93)
Widowed	12.20 (SD = 6.78)
Divorced/separated	14.71 (SD = 8.07)
Married	15.57 (SD = 8.23)

Married residents had a larger pool of people in their network than their counterparts who were not married, widowed, divorced or separated. Divorced or separated residents reported having networks which are only marginally smaller than those of married residents. The literature on older people in the community, however, suggests that such ties, especially for men, are weak and marital break up can disrupt the bond between parents and children (Cicirelli, 1983; Furstenberg, 1981; Hennon, 1983). Finally, the never married had the smallest networks, with an average of 6 people. These network members were primarily siblings, nieces and nephews. Friends are also relatively numerous in this group. A high percentage of their members are similar in age, increasing vulnerability to losses through death and disability.

Contact with Kin and Friends: Are There Differences Between Residents?

Family structure will influence the dependency which older people have upon others for support (Hoyt and Babchuk, 1983). For instance, older people without children have greater contact and express closer ties with siblings, nieces and nephews than older people with children (Bachrach, 1980; Kendig et al., 1988). A lineage hierarchy determines who will be called upon to provide support. Previous research documents that older couples tend to rely primarily upon each other (Day, 1985); older widows tend to rely upon their children (Lopata, 1979) and the unmarried aged turn to siblings or other relatives and friends for support (Johnston and Catalano, 1981; Shanas, 1979). This social support pattern has been identified by Shanas (1979) as the 'principle of substitution'. Whether a similar substitution principle operates for visitors to nursing home residents has not been examined in the gerontological literature.

Table 7.4 shows that there are differences between the resident's marital status and who visits her. Children and grandchildren constitute between 63 to 87 percent of all the visitors of ever-married residents. This result may suggest that with the presence of a child more distant relatives are less visible in the support system of the older person. However, in contrast to the widowed and married residents, children dominate the separated or divorced residents' pool of visitors. They make up over half of the separated or divorced residents' visitors, in contrast to only 26 per cent of the visitors for widowed or married residents. This suggests that divorces can weaken peripheral family ties but not necessarily the core ones to children. Unlike children who feel a filial responsibility to visit, other family members are under less moral obligation to maintain contact.

Brothers, sisters and other relatives are the major visiting groups for

Table 7.4 Relationship of visitor to resident by marital status

Relationship of resident to visitor [a]	Marital status of resident			
	Single	Widowed	Separated/ Divorced	Married
	%	%	%	%
Spouse	-	-	-	7
Child	-	26	56	26
Grandchild	-	40	32	37
Sibling	29	10	7	10
Niece/nephew	40	12	4	12
Other relative	5	2	1	-
Friend				
TOTAL	100% (101)	100% (574)	100% (73)	100% (69)

(a) Excludes kin/friends whom the resident has not seen during the last two years.

the never married residents, accounting for two-thirds of the their visitors. Never-marrieds are three times more likely than their married counterparts residents to have a sibling visit them, and nine times more likely than residents who are separated or divorced to have a niece or nephew visit them. Whereas for the other marital groups there is a tendency to drift apart from their siblings, nieces and nephews in their old age, the never married aged maintain frequent contact with their extended family members (Gibson and Mugford, 1986). This is because siblings, nieces and nephews dominate their pool of potential social support. Anticipating their needs in

old age the never married invest more time in developing strong emotional ties with siblings and friends (Day, 1985). As we can see from Table 7.4, a significant number of the never marrieds' visitors are friends. Twenty-seven percent of all of their visitors are friends, whereas only seven to ten percent of the widowed and married respondents' visitors are friends.

When trying to determine the role family and friends play in old people's lives, a distinction must be made between the presence of people and the giving or receiving of support. Once this distinction is made, the difference between the support networks of married and unmarried elderly people may not be as great. In order to assess the comparative take-up rates in people's networks, defined as the proportion of network members who visit, residents were asked to list all of their kin and friends and then indicate how often they saw them. Table 7.5 shows that the majority of people living in the community maintain contact with their aged relative or friend, although this varied with the marital status of the resident.

As discussed earlier, the never-married residents have smaller social networks than the other marital groups. However, their family and friends are no less committed to them than are network members of other residents. The never-married residents have the second highest take-up rate. Over three quarters of their network members had visited them. Only 22 percent of their network members had not visited during the last two years. Of the people with whom contact had been lost during this period, over 50 percent were siblings, many of whom were too old or ill to travel to the nursing home. The loss of contact with their siblings has less to do with their kin members' lack of commitment to the relationship than it did with bad health (Day, 1985; Gibson and Mugford, 1986). The absence of large numbers in one's network may not be a disadvantage. The important issue is the quality,

Table 7.5 Visitor take-up and loss rate from the resident's network by marital status

Relationship of resident to Visitor	Marital status of resident: Single %	Widowed %	Separated/ Divorced %	Married %
Visit	78	87	57	75
Who do not visit[a]	22	13	43	25
TOTAL	100%	100%	100%	100%
	(129)	(661)	(129)	(92)

[a] This consists of people nominated in the aged person's network but who the respondent has not seen during the last two years.

not the quantity, of social contact. The never-married aged carefully evaluate their needs in life and cultivate friends and relatives whose ties with one another are voluntary in nature (Bøtt, 1971).

Although studies have found that the separated or divorced elderly can have large networks (Antonnucci, 1985), Table 7.5 illustrates that they have the highest loss rate of contact with family and friends. Forty-three percent of the members in their network had not visited the older person during the last two years. Grandchildren made up a little less than two thirds of the family members they had not seen during the last two years. The loss of contact with kin may be due to changes in relationship caused by separation. Friction within the family can also produce conflicts with grandchildren, siblings and friends.

Although widowhood and divorce are conditions under which formerly married people become single, the effect on the kinship system and consequent support network differs markedly between the two groups.

Whereas divorce contracts the network membership, bereavement tends to bring families together and activate ties with more distant kin and friends. It is not uncommon for aged widows to go to live with their children or a sibling after the death of a spouse (Bankoff, 1983). The results of this study support the finding that the widowed maintain strong support networks after the death of their spouse (Kohen, 1983; Mugford and Kendig, 1986). Table 7.5 shows that widows enjoy the highest take-up rate of network members. Eighty-seven percent of their network members have visited them since moving to the nursing home.

Comparison of the widowed to the married shows that fewer members mentioned in the networks of married residents maintain contact with their aged relative or friend living in a nursing home. Twice as many people in the married residents' network had not visited their aged relative or friend during the last two years than in the widowed residents' network. Having a spouse and child may reduce contact with other relatives or friends, who knowing that others are regular visitors, do not feel the need to maintain contact. Although the presence of a spouse is a powerful shield against loneliness, it can also limit developing affectionate ties or exchanging support with extended kin members or friends (Day, 1985).

Conclusion

The Australian aged, like their American and English counterparts, generally are not forgotten by their family members once they move into a nursing home. Many maintain contact with people living in the community, with marital status being the main influence on which kin members visit them. The childless residents were no less likely than residents with children to receive a visitor, mainly because they had more visits from distant

relatives and friends. The presence of many visitors to nursing homes suggests the potential to help families achieve even greater levels of interaction with their aged relatives or friends.

Admission into a nursing home is an emotional experience for most older people. Adjustment to institutional living is made difficult by the separation from familiar routines and surroundings (Tobin and Lieberman, 1976), and the curbing of privacy and freedom of movement (Bennett, 1980). Family members and friends can cushion the impact of institutional living by providing social and emotional support, and offering more personal contact than that provided by staff members or other residents. The presence of the family has the additional impact of decreasing the overall institutional atmosphere of the nursing homes by connecting the home with the outside community. Many nursing homes, however, encourage family members to take only a limited role in the planning and delivery of services for residents. Some directors of nursing homes are reluctant to involve family members in caregiving. Ambiguity exists between the nursing home and family responsibility (Shuttlesworth et al., 1982). In general, family involvement is limited to attending special events or supervising outings. Like residents,families play subordinate roles to professional nursing staff.

In their attempts to standardise and rountinise services to many residents, directors of nursing homes can create unintended generalized rules that serve the goals of the institution more than the individual client. The constraints of time and money, and daily routines, often restrict rather than facilitate, contact between residents and family members or friends. For instance, visiting hours allow nurses to do their work without the interference of visitors but place limitations on when people can enter the

nursing home. Directors do not encourage residents to instal private telephones as it constrains patient transfer. Yet for residents who have family members or friends not living close to the nursing home, who are working or unable to travel, the telephone may be the only means of regular communication. Some government regulations also restrict contact. For instance, regulations concerning bed occupancy discourage residents from staying overnight with their family. Residents (and families) fear that, if they leave the bed unoccupied, they will not be able to return to the nursing home.

Given such constraints, it is not surprising that there exist few programmes in nursing homes which facilitate the meaningfulness of contact for both the visitor and resident. Few homes have visiting rooms that allow people to interact with each other without the presence of other residents or staff members. With others walking in and out of the room, the residents and their visitors may have to censor conversation. Others may hesitate to display physical affection in the presence of strangers.

The establishment of a closer partnership between family members and nursing homes will depend on the degree to which staff members encourage and support family involvement in care programmes. The role of the family in nursing homes can be enhanced by liberalising visiting policies, by providing amenities such as lounges, by providing counseling services to family members, and by educating staff members to understand and accept the important role that family members can play in improving the quality of care. An adoption program for residents without family or friends can be established, and for those with family members or friends who cannot visit, telephone contact encouraged.

CHAPTER 8

The Regular Visitors - Who are They?

The previous chapter has shown that older people do receive visitors. While it is of some comfort to discover that residents are not without visitors, a frequency count of the visitors who cross the doorsteps of nursing homes explains little about the factors that influence which people are more likely to visit regularly. A full understanding of who visits and how often depends upon identifying factors that bring people together or push them apart. Equally important is the question of whether the decision to move into a nursing home has affected the quality of interaction between the resident and her family. Such a decision can introduce strain into the relationship and affect both the quality and frequency of contact. This chapter will first disentangle the factors which are more likely to influence visiting frequency, and second use qualitative data to highlight changes in relationships once the older person has moved to the nursing home.

Visiting Frequency - What Factors Determine It?

Using a similar analysis to that reported in the Hook et study, Pearson product-moment correlations were used to examine the factors that influence frequency of visiting. In order to meet the statistical requirements of Pearson product-moment correlations, the nominal variables were recorded into dummy variables. As Hook et al. (1982:426) note the polytomous ordinal variables used in the analysis satisfy 'the criteria for use in regression-based stastistics outlined by several examinations of the robustness of the interval level assumptions in this type of analysis'.

This study extends the analysis of the Hook et al (1982) study. Their sample only included people who had been visitors to the nursing home during a two week period. This procedure left out other family members or friends who could have been actual or potential visitors, if a longer time frame had been used. It tends to under-represent certain groups of people, such as young people who because of their school commitments may not be regular visitors. To overcome this methodological problem, residents were asked to list all of their family members and close friends. Data was then collected on the characteristics of people mentioned in the residents' network and how frequently they visited (see chapter 7). Hook et al's study focused only on the characteristics of the residents and visitors. While including the effects of such factors on visiting patterns, the present study also includes the effects of the characteristics of the nursing home and people's perceptions of their relationships with others. This will allow us to determine whether the characteristics of the nursing home play an equal or more important role than the other factors. The following hypotheses are raised:

Features of nursing home:

(a) visiting frequency is inversely related to the distance travelled by the visitor;

(b) visitors are more likely to visit when the nursing home encourages family involvement.

Relationship between resident and visitor:

(a) visiting frequency increases according to the degree of closeness of the kinship relationship, (b) perceived quality of relationship, and (c) when resident and visitor are of the same gender.

Characteristics of Visitor :

(a) females are more likely than males to visit frequently;

(b) those in the work force will visit less often than those not employed.

Characteristics of Resident :

(a) females, and married persons receive visitors more frequently than males or the never married, divorced or widowed;

(b) visitation frequency declines with length of stay in the nursing home.

Table 8.1 indicates that the type of relationship between the resident and people mentioned in the network are important determinants of the frequency of visiting. Three measures of the type of relationship between the resident and network members used in the analysis were the perceived quality of the relationship, kinship distance and whether the potential visitor and the resident were of the same or different sex. To measure the quality of the relationship, residents were asked to give a brief history about their relationship with each person mentioned in their networks. The qualitative data were then coded into whether the residents felt that a positive relationship (e.g., 'we have always been close'; 'she is the best daughter a mother can have'), a neutral relationship (e.g., 'I have never had much to do with my grandchildren, we just do not know one another'; 'I do not like or dislike my brother, we have just lead separate lives since we moved away from home) or a negative relationship (e.g.,'we do not talk to one another'; 'I have never liked my sister') exist between the two individuals. Kinship distance was measured in terms of the descending order of kin ties (e.g., spouse, child, grandchild, sibling, niece and nephew, other relatives and friend); while the resident's sex was matched with their network members.

Table 8.1 Relationship between Frequency of Visiting to Four Categories of Independent Variables

Independent Variables	Pearson's correlation with frequency of visiting Nursing homes pooled
Characteristic of Home	
Distance travelled	.54 (p<.001)
Nursing home environment	.10 (p<.001)
Relationship	
Kinship distance	.16 (p<.000)
Quality of relationship	.57 (p<.000)
Same/different sex	-.08 (p<.005)
Attributes of Visitor	
Sex	.06 (p<.02)
Age	-.04 (p>.12)
Marital Status	.08 (p<.01)
Employment	.02 (p>.27)
Attributes of Resident	
Age	-.18 (p>.001)
Sex	.09 (p<.01)
Marital Status	.14 (p<.000)
Length of residence	.05 (p>.06)

The single strongest correlation among these three variables, and all variables in the analysis, was between the resident's perceived quality of the relationship and visiting frequency (r=.57). People with whom residents felt they had a good relationship were more likely to visit frequently than family or friends whom the residents felt indifferent about or disliked. This suggests that contact with an aged person is not necessarily tied to kinship or

obligation. Rather people who find the contact rewarding will want to see one another regularly. People find it difficult to sustain regular contact if the relationship is based on tension and lack of affection for one another. When the kinship relationship is examined, more distant relatives and friends were not as likely as the immediate family members to visit regularly. While residents may have a wide range of potential ties with people, they usually turn to close family members, such as a spouse, children or siblings for suport. As Hook et al (1982:427) state this finding 'strengthens the claim that support networks for institutionalized elderly continue to come from close relatives'. Perhaps residents and their families expect that children should visit regularly while they may not hold similar expectations of distant relatives. There was also a significant relationship between whether the visitor and resident were of the same or opposite sex. Network members who were of the same sex as the resident were more likely to visit often than were those of the opposite sex. This probably reflects the sexual stratification system operating in our society. People are more likely to share recreational activities and confide in members of their own sex (Mugford and Gibson, 1986; Kendig et al., 1988). This may lead to establishing closer ties with people of the same sex.

The social barriers to a visit, as measured by geographical distance from the resident, and the nursing home's influence on family integration, were factors influencing the frequency of visiting. The geographical location of the visitors was significantly related to how frequently they visited the resident, with individuals who travelled greater distances visiting less often. This highlights the importance of selecting a nursing home that is located close to significant others.

In recent years, a great deal of attention has been paid to the examination of more personalised institutional care and its effect on patient morale and family relationships. Nursing homes can encourage or discourage the involvement of the resident's family and friends through their policies. For instance, Montgomery (1981) found large differences in families integration with the residents' lives in three nursing homes.

To assess the nursing home's influence on the frequency with which people come to visit their aged relative or friend, a measurement of the nursing home's policies on family integration was constructed. Directors of nursing homes were asked whether (1) they offer services to the resident's family or friends; (2) they send reminder visit cards or make telephone calls to relatives; (3) they enforce limited visiting hours; and (4) the nursing home has a special visiting room so that the resident and visitor can enjoy privacy.

A score of four indicates that the nursing home encourages family involvement, while a score of zero can be interpreted as showing that the nursing home lacks specific policies which encourage the family to be involved in the life of the resident. There were great variations in the scores between the eight nursing homes. The average score was 2.1 (SD 1.3); with Nursing Homes A and C scoring the maximumpoints, Nursing Homes B and D scoring between 2 and 3 points, and Nursing Homes E, F, G and H scoring low scores of one or zero (see chapter 6 for a description of the nursing homes). Although the influence of the nursing home on family integration was significantly related to the frequency at which people visited, its correlation is not as numerically high as one would expect (r=.10). This can be partly explained by Booth's observation that improving the character of the residential environment does not have a major impact on the ties that

exist between people prior to admission or some of the damaging consequences institutional living has on social interaction.

> Sociologically, the differences between regimes must ... be seen as a veneer that decorates the massive uniformity of institutional life, and catches the eye for precisely that reason (Booth, 1985:205-207).

Such policies can only go so far in removing the detrimental effects of institutional living. The disorienting and controlling features of institutions are present in all homes. Nursing homes operate from the same principle of client dominance as institutions in general. The routine of nursing homes, made necessary by staff and economic factors, encourages treating patients as collective inmates.

Although some of the attributes of the visitor and resident confirm the statements made in our hypotheses, the numerical value of Pearson's correlation indicates that these factors explain only a small percentage of the variance in visiting frequency. The age, marital status and employment status of family and friends were not significantly related to how often people visit. However, female network members were more likely than male network members to visit regularly. This can be explained in part by the cultural identification of women with emotional support and the conditioning of women to network maintenance. Studies have shown that women are more likely than men to take greater 'responsibility for activities such as sharing intimacies, remembering birthdays, organising gatherings, and exchanging mutual aid' (Mugford and Kendig, 1986:51). In addition, females generally have a lower participation rate in the work force than males. This may give them more time to visit during weekdays and office hours.

Some of the characteristics of the residents did help also to determine who was more likely to receive regular visitors. Female residents had more frequent visitors than male residents. This collaborates the finding of a number of studies which have found that women are more concerned about maintaining close bonds with family members, and in particular, with siblings and friends (Albrecht and Bahr, 1979; Mugford and Kendig, 1986). Their investment in developing such ties results in others being more concerned and willing to provide support.

Contrary to expectations, the never married residents received more frequent visitors from their network members than the married residents. An explanation for this finding could be that having a large network may diffuse how frequently people will visit. Network members may work out a roster of who will visit, thus reducing the probability of one individual visiting regularly.

Although it was expected that length of residence would be negatively related to how often people visited, no such relationship was found. Montgomery (1982) found that visiting frequency decreases with length of residence. However, the Montgomery study included a large number of demented and severely handicapped respondents who had lived in the nursing home for many years. Poor physical and mental health may discourage visiting. The sample of the present study is biased towards the less disabled aged. None of the residents had physical and mental disabilities that would inhibit communication (see chapter 2).

The Effects of Institutionalisation on Residents' Relationships

The previous section has shown the factors that can influence visiting. However, this does not provide any information on any changes in the amount and/or kind of social contact since moving to the nursing home. In order to address this question, the 90 residents in the in-depth study were asked to state whether they felt that they saw more, about the same, or less of their kin since moving to the nursing home. Over three-quarters of them felt that they saw less of their kin since moving to the nursing home. If the older person had previously lived with a family member then it can be assumed that opportunities for daily contact would be greatly reduced when the older person moves to a nursing home. In addition, when the older person was living in the community, she did not necessarily have to wait for others to visit her at home. She probably had a greater opportunity to visit her family, thereby increasing contact with them.

Institutional life can inhibit communication (Kahana et al., 1985). Living in shared quarters can have an impact on behaviour patterns. For instance, some people may avoid talking about intimate topics. Others may hesitate to display physical affection in the presence of strangers. With such factors affecting the quality of interaction, relatives may not visit as often. Some family members may be disturbed by the presence of mentally and physically disabled residents.

> I try to see her once a week but my wife and children do not come as often. My wife gets depressed seeing so many old people just sitting in their chairs and not doing anything. I also find it depressing and often I just sit with my mother and say nothing. This may sound cruel but I hate going to see her at the nursing home. I sometimes can not recognize my mother amongst all those other residents. She has just changed so much (Mrs Read's son, married - 40s).

The process by which families and health professionals go about excluding the older person from the decision to enter a nursing home (see chapters 4 & 5) can weaken family support, perhaps because of the family's guilt and remorse over their decision, or the older person's resentment of the rejection by her family.

> Mrs Yates: My son dumped me here, there is no other word for it. No one told me I was going to a nursing home. I will never forgive him for doing this to me.
> Vic: Does John come to see you often?
> Mrs Yates: No, he comes once or twice a year. And there is so much tension between us that you can cut it with a knife. He even changed his telephone number so that I can not call him (widowed, 68 years old; see pp 74,128).

> Mrs Renzi's granddaughter: I try to visit her as much as I can but it is difficult for me because she has a way of making me feel guilty. She is always asking me when will she return home. And I know she never will. She can't see my point of view. This makes it difficult for me to talk to her as we used to (married, age - 30s; see pp 75,83,90).

Not all residents, however, reported a decrease in their level of contact with kin. Sixteen and 10 per cent respectively indicated that there had been no change or an increase in how frequently they saw their kin. Residents who reported an increase in the interaction with family members spoke about how institutionalisation had improved their ties. As the nursing home staff met the technical needs of the aged person, the family was able to provide more affectionate support. The feeling of being a burden to others, and the tension created by this perception, was eliminated. Some felt that their families had become more concerned and 'made time' to see them.

In addition to observing changes in the frequency of contact, it is important to note whether institutionalisation has changed the nature of the relationship between residents and their next-of-kin. To determine the type

of changes that had taken place in relationships since the move, both residents and their next-of-kin were asked to describe their relationship and to comment on whether they felt institutionalisation had affected their relationship with each other. The data were coded in terms of institutionalisation improving ('we are much closer now'), deteriorating ('ever since I came here things have been worse between us, we are always fighting') or remaining the same ('we have always been a close family, things have not changed).

Table 8.2 illustrates that over half of the residents and 43 per cent of their next-of-kin felt that a change in their relationship with one another had occurred since moving to the nursing home. Contrary to the popular view that placing a relative in a nursing home can only create negative feelings, about one quarter of the residents and their next-of-kin mentioned that their relationship with one one another had improved since the move. For the family, they no longer had the constant worry; for the older person, she no longer felt a burden. The vicious cycle of dependency had disintegrated for both parties, allowing them to explore expressive social relations.

> Mr Baker: My daughter and I are good friends but we always kept our distance. When I was living at home, before I came here, although my daughter never said so, I think that I was a nuisance to her. She worried about me and visited more frequently than she usually did. I felt I got in her way and this was changing our relationship. Since I have moved here things are back to normal between us. She comes to see me occasionally and I ring her (widowed, 75 years old).

> Mr Bailey's daughter: My father and I have a very strange relationship with each other. We don't see each other often and we led independent lives from each other. But we are close although it may be difficult for others to see that. We respect each other's independence. When he was living at home, I mean during the last couple of months before he moved to the nursing home, he needed help with housework and cooking. It created a strain in our

Table 8.2 Residents and their next-of-kin's perception of how placement into a nursing home has affected their relationship.

Type of Change	Resident %	Next-of-Kin[a] %
Positive	24	23
Negative	30	20
No change	46	57
Total	100 (90)	100 (79)

[a]A total of 79 next-of-kin were interviewed. In 8 cases, the residents had no next-of-kin, and in the remaining 3 cases the next-of-kin contacted passed away before an interview could be arranged or permission to contact the next-of-kin was not granted by the patient.

> relationship is back to the way it used to be. In fact, it is better because I know he is cared for and that eases my mind (separated, age - 50s).

Residents who while living in the community had relied mainly on their families for social activities discovered a new self in the communal living of the nursing home. Some of them developed interpersonal skills and interests that brought them 'out of their shells' and lead to an improvement in the quality of their interaction with others.

> Mrs Greene's daughter: I think moving into the nursing home has been the best thing that has happened to my mother. When she lived with us, she never spoke to the neighbours or made friends. She was totally dependent on the family for friendship. Ever since she has come here she has matured as a person. She has gotten out of her shell. She has made

> many friends, especially with Mrs. O'Brien. I have much more to talk to her about and do not feel that she is lonely if I don't talk or come to see her (married, age - 50s; see pp 72,80,82,92,166).

For others, the trauma of institutionalisation can result in the weakening of family ties. More residents than their next-of-kin reported that their relationship had 'taken a turn for the worse' since moving to the nursing home. While a little less than a third of residents felt this way, only 20 per cent of their next-of-kin felt their relationship with their older relative had suffered. Older people felt betrayed by their family's decision.

> My oldest son signed my husband and I in here. I was ill at the time the decision was made so there was not much I could do. I would have been more opposed and put up more of a fight had I not been ill. I can not believe my sons did this to us. My husband died shortly after he came here. I think he died of a broken heart. My eldest son use to visit every week but all I could say to him was to take me back home. I'm sick of this place but they will not take me into their home. I am very upset with my sons. They do not come to visit as often (Mrs Wright, widowed, 82 years old; see p 70).

The family members of these residents felt that their 'grumpy' relative was playing on their guilt feelings and coercing them with 'unreasonable demands'. The relationship centred around a constant battle of pleasing the displeased. Fighting a losing battle, relatives restricted their interaction to a quick ceremonial visit.

> My mother and I always had a strange kind of relationship. We have always fought with one another but things have got worse since she moved into the nursing home. She is constantly reminding me of how I have let her down by putting her in the nursing home. She complains about the other residents, the food and staff. I usually see her once a week for about 15 minutes. Most of that time is spent shouting at each other. I often leave the nursing home thinking that I will never go back to see her.

> But I always do. She has no one else who will visit her (Mrs Telling's son, never married, age - 40s; see p 120).

Not everyone, however, felt that the move to the nursing home had affected their relationship. Almost half of the resident and their next-of-kin reported no changes in their relationships. Either they continued to express close feelings for one another or they maintained contact without affectionate interaction.

> My four children and I have always been close. My decision to live in a nursing home has not changed any of that (Mrs Rowland, widowed, 85 years old).

> I have six children but I have never been a family man. After the divorce I led a separate life from them. My moving to the nursing home has not changed any of that. I don't even know where they live. In fact, they may not even know that I am living in a nursing home (Mr Cox, divorced, 67 years old).

Conclusion

Visiting an aged relative or friend is a voluntary decision although it may be motivated by a sense of obligation or guilt. Relatives may choose to deliberately limit their contact or they may unintentially restrict their interaction with the older person by selecting a home that is located at a distance from them.

The location of the nursing home is an important factor in determining frequency of visiting. Selecting a home that is located nearby may help to increase interaction with the older person. Too often family members accept on behalf of the aged person (see chapter 5) the first available bed that comes along. As family members indicated in their stories (see chapter 3) they often do not start looking for a home until a crisis forces them to do so. Care is needed desperately. Under these

circumstances less attention is paid to the location of the home. An equally important criterion when selecting a home is whether the director's policies encourage family participation. Nursing homes which do not make feel people welcome receive less frequent visitors but the effects found in this study were small.

Of course, whether or not people will be frequent visitors is not solely determined by the location of the nursing home or the director's policies on family involvement. Consistent with the results reported in the Hook et al study, the characteristics of the residents and of the visitors are more important influences on frequency of visiting. However, the ability of such factors to predict who will receive visitors on a regular basis is marginal. While a person's employment status or gender can place the visitor in situations where frequent contact is made more plausible, maintaining regular contact may be better explained in terms of the depth of ties between people. If people perceive their contact to be mutually meaningful and rewarding, problems of access, such as limited time and competing demands, can be managed. The older person's change of address will not alter such ties if a strong relationship exists between the older person and the network member.

Nursing homes do not necessarily weaken family ties. For some residents the move can improve their relationship with family and friends. This raises an interesting question - is there an association between involvement in the decision making process and the quality of contact with kin after placement? While it is beyond the scope of this study to examine in detail the quality of relationships between residents and their families, the results suggest that the cost of excluding the older person from the decision making process can reduce the quality of family relationships. In some

cases, poor family relationships may explain the lack of involvement of the older person in the decision making process on entry, and this exclusion can in turn worsen a relationship further. There is a need for more study of family relationships in the context of a life history approach which captures more than a snapshot view of the older persons' feelings about family ties once in a nursing home. Such an approach allows the researchers to study more than simply the reaction of the older person when she has entered a nursing home. This will help us to determine the nature of family relations and examine the impact of entry into a nursing home upon relationships. While it is important for consumers to carefully assess the features of the nursing home, the main policy impact on visiting and quality of life may well be the maintenance of good family relation upon entry.

CHAPTER 9

Conclusions and Implications

This study has been concerned primarily with consumer viewpoints on the processes by which people come to enter a nursing home and their experiences once there. Their perceptions provide important lessons in the evaluation of institutional living. It should, of course, be understood that personal intepretations are always formed in, through and by the public arena (for a discussion of such issues see Kendig and McCallum, 1989).

The interviews with residents and their kin members were held in 1982 and 1983. Since this period, a number of changes have been introduced in the field of Australian aged care (Commonwealth Department of Community Services, 1986). Despite these policy developments, the structure and utilisation pattern of institutional care that has been established since the beginning of the century probably has not changed in any major way. The personal issues and organisational incentives surrounding the processes of older people entering and living in a nursing home remain. The concerns raised by the findings reported here are recurring ones, and are similar to those mentioned in the much earlier study by Tobin and Lieberman (1976) in the United States and Townsend (1962) in Britian. These studies deal firstly with the inability of the aged to control decisions that affect their life; and secondly, with the constraint of limited resources in achieving the rhetoric of well-intended policies.

The remainder of this chapter will review and build upon the themes developed in earlier chapters. Specific attention will be payed to the implications of excluding the older person from the decision processes of entering a nursing home and evaluating how current policies influence those

who live and work in nursing homes. It is recommended that policy makers pay more attention to what the aged, their families and those working in nursing homes have to say about their perceptions of what the future holds for them.

Overview of Approach

The fact that human beings are capable of voluntary action within the influence of external structures poses a challenge for the social scientist. This challenge requires that the social scientist uses a variety of conceptual frameworks and methods to understand the actions of people. Too often researchers restrict their theory and methods to a single paradigm. Theoretically, the study of social ageing has been dominated by one school of thought, structural functionalism, (Marshall, 1979) and most of the data has been collected via quantitative methods (Minichiello et al., 1988). However, as this thesis has shown much can be gained by combining a micro with a macro perspective, and using a multi-method package.

As it was discussed in the opening chapter, the micro and macro levels of theory are too often viewed as opposing and uncomplimentary, and serving different purposes. The micro perspectives focuses on social interaction as a social process, and how each individual interprets and assigns meaning to a specifc event, behaviour or situation. Researchers who work within this paradigm usually ignore the influence of the larger social system in which the specific meanings and interpretations take place. The macro perspectives focuses on how individuals are influenced by the social fabric of society. As a consequence, critics have argued that this perspective ignores 'the fact that the features (structures) of society are maintained and changed by the actions of people, and are not autonomous, or self-regulating' (Manis

et al., 1978:7). These two perspectives, however, can be applied in a complimentary manner.

Just as different theoretical perspectives are needed, so too are different research methods. No only single method can capture all social phenomena associated with the process of older people entering and living in nursing homes (chapter 2). In order to illuminate different aspects of the institutionalisation process, the study used a variety of qualitative and quantitative methods. The socio-medical survey was used to identify social patterns in people's pathways into nursing homes and relationship with others, highlight differences between categories of people, and through correlation analysis (chapter 8) explain which factors are determinants of behaviour. In-depth interviews and participant observation were used to extract the complex picture of individual perception and action (chapter 3, 5). In these ways the thesis has illustrated the value of a multi-method approach to synthesize findings and produce a more rounded conceptual explanation of the phenomena under study.

Methods were selected because they produced the kinds of information which was most relevant to the question being asked. For instance, unstructured interviews and participant observation were used to collect information on how nursing home directors make decisions to recruit residents. The focus was to identify the informal rules that nursing home directors apply in their admission criteria. An analysis of the nursing home file would have produced different results. Indeed, the admission criteria found in the nursing home file would probably reflect how nursing homes officially announce their recruitment policies. The aim of the chapter, however, was to explain how directors of nursing homes interprete formal policies.

In this thesis, both qualitative and quantitative methods were applied to study peoples' experiences in entering and living in a nursing home. These experiences were viewed as social processes that evolved out of the influence of both structure and actions. For example, chapter 3 and 4 showed that a person's pathway into the nursing home is partly influenced by their prior living arrangement, marital status and family support. This macro approach suggests that people with similar socio-structural attributes tend to exhibit common patterns of behaviour. Using a micro level of analysis (chapter 5), however, showed that these factors only set a broad boundary for possible action. Individuals as social actors may assign different meanings to their situational factors (such as their living arrangement, marital status, family support) on the basis of their interaction with themselves and others. This was illustrated in the typology presented in chapter 5. What placed an elderly person in a certain decision making situation was not solely determined by their social attributes but by how people were giving meaning to their situation through interaction with themselves, family members and health professionals. Perceptions of managing/not managing, entitlements and obligations played a crucial role in determining involvement in the decision making process.

The additional insights afforded by multiple research approaches were also shown in older people's experiences after entering nursing homes. Chapter 7 described the quantitative factors that may predict who visits older people in nursing homes. Chapter 8 provided additional qualitative data which showed that visitation patterns are influenced heavily by how people define their relationship with one another. A relative or friend may possess all of the characteristics that may help a social scientist estimate their level of

visiting at an aggregate level, such as living near the nursing home or having a close kinship tie, but this does not necessarily guarantee that such action will take place. Researchers need to understand that each person engages in a unique form of behaviour involving his or her interpretation of the situation and acts on the basis of that intepretation.

The interplay of structure and action was also highlighted in chapter 6. Nursing homes in Australia are regulated by public policies to the extent that they must meet state and federal standards in order to receive subsidies. Directors of nursing homes nonetheless do exercise some control over the implementation of formal policy. This raises some practical consideration for government when it introduces public policies. The relationship between policy and its implementation can not be taken for granted. The actors who are involved with implementation 'frequently operate in ways which create or transform or subvert what might have been regarded as the policies handed down to them' (Hill and Bramley, 1986:139). All work, however closely controlled and supervised, involves some degree of discretion (Barrett and Hill, 1984). This is because the people who are responsible for the delivery of services have 'subordinate authority' delegated to them and are involved in the discretionary application of rules to actual situations. As showed in chapter 6, directors of nursing homes exercise considerable discretionary power.

Overview of Findings

The people in this study spoke about the importance of social factors behind the institutionalisation decision (chapter 3). This does not mean that health factors were not mentioned or unimportant. Indeed, if the sample had included the more disabled residents, health factors would probably have

emerged as a dominant theme in people's stories for seeking nursing home care. However, it is too simple to say that some older people are admitted into nursing homes because they are physically and mentally no longer capable of managing with independent living. The importance of the meaning people attach to their situation, and how this in turn, influences their actions was identified as an important determinant influencing the decision to seek nursing home care. People's beliefs that they can no longer manage, or the desire to avoid becoming a burden to others, or the inability of families to provide support or the older person accepting it, are important factors moving a person into the nursing home (chapter 5). There is tremendous diversity in the possible interpretations of the situations in which people find themselves (chapter 3).

An older person's demographic or social situation does not predict fully who will use or not use nursing home care. While it has been well documented that those old people without family ties are over-represented among the institutionalised aged population (Howe and Preston, 1985), this obscures two other important facts. First, as shown in chapter 5, there are many other residents who do have a family and who are also admitted to nursing homes. Second, as Russell (1981) points out, the lack or loss of family is only one of a cluster of characteristics shared by the institutionalised elderly. They are also characterised, as a population, by a series of diverse personal and social experiences. What separates the experiences of elderly residents admitted into nursing homes from each other, and from people not admitted into a nursing home, is how they perceive their situation and the meanings they attach to them. This also helps to explain why some people were involved in the decision making process and others were not. For this reason it is methodologically naive to single

out any one item as the explanatory variable that explains why older people use nursing home care.

The analytical framework of symbolic interactionism sheds considerable light on the manner in which human action follows a logical course. While government reports may see some of the residents in this sample as having been 'inappropriately' placed in a nursing home, for the older person who decided to seek nursing home care and for family members who decided on behalf of the older person, the decision was appropriate, although not always desirable (chapter 3, 5). It is important to remember that institutional care is often spoken of by some residents and their kin as an appropriate solution. As reported in another study (Wilkins and Hughes, 1987), respondents in this study did not see the choice between living <u>at</u> home or <u>in</u> a home as a real alternative. Wilkins and Hughes correctly observe that:

> ...it was a choice between enforced independence and enforced dependence. Independence and community care are positively valued when set against dependence and institutional care, but is it arguable that, for many residents of homes for the elderly, the quality of many aspects of their lives was as good or better than they might have experienced in their own homes (1987:197).

They go on to note that 'researchers and practitioners alike often seem prepared to grant greater credence to the expressed desire of elderly people to remain in their own homes than to the desire of those in institutions to remain there' (1987:198). A fundamental risk in research practice and policy formulation thus is the tendency to impose views of others on the elderly. While for many of us living in a nursing home may not be a desirable option, for some it is, and for others it may be their only 'choice'.

It is in this context that policy recommendations are most appropriately analysed and evaluated. Policy makers, as will be discussed later in the chapter, will need to take into account the reasons for the actors seeking residential care rather than the traditional concern for tidy policy. Perhaps some of the residents included in the study would have been admitted to hostels rather than nursing homes if one used current criteria of assessment rather than that proposed by the previous dictates of policy. Nevertheless the same social forces may have operated in the processes drawing them towards institutional life. The criteria stated in the admission papers may have no connection with the perceived reality of the actors (chapter 3).

The findings of this study provide evidence that most older people are a minor participant in the decision to enter a nursing home. Over three-quarters of the residents felt that they had 'very little or no say' in the decisions to move or select a nursing home. Family members are seen as the most influential actors, although there were differences in which actor was likely to be selected depending on living arrangement (chapter 4). However, this does not mean that family members are 'dumping' their aged relatives into nursing homes at the first opportunity that presents itself. As the stories of the next of kin revealed they paid a high emotional price for excluding the older person from such decisions. Because many families believe that they should provide more support than they can manage, they can feel trapped into acting in a conspiratorial manner with directors of nursing homes and general practitioners. They see no other alternative.

Family members often made the decision on behalf of the older person (chapter 4), and institutionalisation was usually seen as being the only alternative rather than a desirable choice. Contrary to the image of family members that is often portrayed in the popular press they do not 'dump'

their aged relatives in nursing homes. The results of this study, as well as other studies (Day, 1985; Kendig, 1986), clearly indicate that family care giving is not on the decline in this country. Most dependent older people in the community will at one point or another live with a relative who provides support comparable to that offered in residential care (Doty, 1986; chapter 5). While it is true that family members play a major role in deciding when and to which nursing home the older person will go (chapter 4), they only begin looking for a home when they can no longer cope. Indeed, the popular media portrayal of the irresponsible family was not supported by the results of this study. Several of the case studies presented in chapters 3 through 5 showed that family members were disturbed about their decisions. They realised that an elderly person in a nursing home has few rights and dignities, and that they have played a role in curbing the patient's former privileges. Many family members do feel guilty about their part in the admission history. Yet even in these difficult and stressful circumstances, they try to reconcile their position and continue strong expressive links with relatives.

Family members generally maintain regular contact with their aged relative living in a nursing home (Ch.7) Institutionalisation, however, can change people's relationships with one another (chapter 8). In some cases, institutionalisation can result in a strengthening of family ties or renewed closeness. As the nursing home staff is looking after the daily needs of the aged persons, the family can concentrate on providing emotional support. The aged person and her family are no longer bound to the strain and demands of the caregiving relationship. Alternatively, expressive bonds with family may be weakened, perhaps because of the family's guilt and sadness over the move, the older person's resentment of being pushed out of

their home, or their inability to interact with one another in an institutional setting. An important factor determining family interaction, however, will be the past history of the relationship.

An important lesson that emerged from the interviews with 90 older people living in nursing homes and their next-of-kin is that the current health and community care system fails to maintain the elderly at home (chapter 3). When the suggestion that the older person should move to a nursing home is raised, very few of them think of community services as a replacement for family care. Consistent with the results of other studies (Kendig, 1986), the respondents in this study obtained most of their help with household or personal tasks from family members rather than community services. Of those who were clients of community services, few received help for long periods (see chapter 5). Community services were often arranged by a family member, or health professional, as an intermediate measure before admitting the older person into a nursing home. With the inability of family support to meet increasing or continuing need, nursing home care is the only alternative.

Reasons for not using community services varied. Many were not familiar with available services; others preferred self help over state or charity help; while a few mistrusted the motives of the service providers or did not want to publicise their dependency. The respondents' message to policy makers was clear. They must be provided with a third choice. An 84-year-old widow ended the interview by saying 'tell them in Canberra to give old people a fair go.' The fundamental issue is that policy is being formulated without direction from those it is being formulated for - the frail and dependent aged.

Ethical, Quality of Life and Quality of Care Issues

The question of who makes the decision to secure nursing home care is important in determining the residents' experiences once in a home. It also raises questions of ethics, quality of life and quality of care. The ethical question centres around the degree of informed consent - to what extent have family members and health professionals kept the older person out of the decision making process?

The effects of being a silent third party in the decision making process for the older person were loss of trust in others and resentment because of the deception used by family members and health professionals in placing that person into the nursing home. Over a quarter of the 90 residents felt that their rights had been violated because they were only informed about moving to the nursing home after the administrative arrangements had been made. A key question that is slowly surfacing in the aged care debate in Australia is whether it is morally right to proclaim the family as the natural guardians of the aged. Should aged persons have legal rights to safeguard their participation in the decision making process?

The quality of life in a nursing home revolves around the aged person's ability to adapt and continue to enjoy life. Residents who made up their own minds to enter a nursing home or who with others jointly agreed with the decision were found to be happier than those who were excluded from the decision making process. If a person's happiness is influenced by the level of involvement in the decision to live in a nursing home, then this may partly explain why some residents adjust, and others do not, to institutional living. As parties involved in excluding the older person from the decision making process family members, health professionals and

directors of nursing homes may be effectively adding to the residents' dissatisfaction and thereby creating 'unadjusted' residents. This exclusion may partly explain why institutionalisation can have substantial negative effects such as increased anxiety, low self-image and feelings of hopelessness and helplessness (Kasl, 1972). Not having had much control over the decision to move out of their homes or any choice in the selection of a nursing home, these people feel that they have lost their hold on life. Involuntary relocation may contribute to the high mortality rates found in nursing homes and difficulties in adjusting to living in a home.

The quality of care question touches on the awareness of health professionals of the needs of their clients. The older person is seldom the only client. Family members, and in particular wives and daughters, are recognised as 'the hidden patients' (Fendler and Goodrick, 1979). When it comes to assisting family members to obtain institutional care for their aged relatives, health professionals are more willing to address the stress needs of the 'family' client than the needs and fears of the aged client. If the aged are viewed as grateful and passive recipients of services, and not given an equal say in the discussion to seek nursing home care, then the current aged care health system will have limited effectiveness in enhancing well being. Aged persons often are passive recipients because they are not listened to.

If the healthier residents, who are capable and willing to communicate their stories, saw themselves as minor actors in the decision making process, then we would expect a much higher proportion of the more disabled residents to have had life decisions made for them by others. For some of the severely handicapped residents, especially those suffering from senile dementia, there may be no choice but to have others act on their behalf. For many others, this does not have to be so. Although there has

been considerable impetus to include the aged person in geriatric team assessments, the bureaucratic pressures to make a quick decision, and the health care bias towards institutional care (Gibson, 1984), give the older person only a 'symbolic chair' and a misleading hope of alternative care.

Another factor to consider is the government's push to restrict admission to nursing home to higher dependency patients. Such a policy may inadvertently reduce the quality of life for those who live in nursing homes. For instance, an increase in the number of physically and mentally disabled patients may foster a pessimistic outlook in those who work and live in nursing homes. Staff members might well adopt the view that patients are work objects, and limit their interaction to providing instrumental care, thus creating an even greater gap between what Goffman (1961) refers to as the 'us and them' found between staff and patients. Others feel that creating a more dependent resident population may lead to poorer staff recruitment and higher staff turnover, and this in turn, will affect the quality of care (Phillips, 1987). Given the strong association between mortality and level of dependency, nursing homes run the risk of enhancing their reputations as places where old people go to die. Directors of nursing homes fear that with a larger resident population requiring extensive care the overall quality of care and the dignity of patients will be reduced (Murphy, 1988). A trend towards more technically regulated care, such as catheterization to control incontinence or nasogastric tube feeding regulation by automatic machines to reduce time spent to feed patients, is made more plausible.

Such policies could also add to the popular misconception that old people are frail and dependent. Given the association between visiting and the health of residents (chapter 8), such a perception of the aged is a disincentative to maintenance of social contact with them. Seen as places that

house mostly sick, incontinent and senile residents, family members may seek to avoid nursing homes. Family members could then find it an even more difficult decision to place their aged relative in such an environment (chapter 3). The resulting isolation, or desolation, as Dowd (1984:80) states 'further reinforces our perception of the aged as strange, different, and sick'. As cited in recent publicity (Murphy, 1988) this may give rise to feelings of resentment not only amongst those who work in nursing homes, but also amongst the public at large. Policy makers will need to reconsider these indirect and long term impacts of current policies.

Policies affecting the aged have been enacted with little attention to the needs and preferences of the aged consumer (Brown et al 1986). Again services are based on providers' assumptions of what the aged require, rather than on what the aged express as their need. The low usage of community services may be explained not only in terms of the limited services available, but also by the aged person's perception that these services are not appropriate to their needs and preference.

The Family Dilemma - Too Much or Not Enough?

Family members are key decision makers in seeking and selecting nursing home care (chapter 4 and 5). The question is how 'key' are these decision makers if they have no real choices? The family's decision is often constrained by inadequate and ineffective community resources that fail to assist them in their efforts to maintain the older person at home.

In their stories, families emphasized that nursing home care was their last choice (chapter 3). It is last because the initial family response is not to place the aged relative in an institution but to try to meet the daily needs of the older person in the community. The lack of options creates a

trap for families. As their efforts failed, the perceived choice was between continued family support or institutional care. On the one hand, the decision to institutionalise an aged relative can be viewed as the neglect of family responsibility. On the other hand, the emotional and social means to maintain the older person indefinitely in the community are not adequate.

The situations families find themselves in is partly the result of the politics surrounding the question of what is the politically-defined role of the state in family care of the aged. Public policy options in the aged care field must be evaluated in terms of the social objectives being pursued.

> Is the objective of family support policies to deter or postpone institutionalisation by motivating family members to provide informal care that they would not otherwise have provided? Or is the purpose to support families in providing care that they would have provided anyways in such a manner that such care does not impose an excessive burden? Is it important that family members themselves provide the care or is it an acceptable policy goal to provide or to enable family members to purchase paid home care that they would not otherwise be able to afford? (Doty, 1986:53).

Doty's questions focus us in the direction of the 'thorny policy conflict between the public's concern with the needs of a dependent population and the presumed right of families to decide most matters privately, without interference by the state' (Osterbusch, 1987:217). It is in this arena that we find two very different approaches to the kinds of services offered and, to whom such services, should be offered. The debate centres around the issue of whether responsibilities lie in the hands of the public or private domain.

An underlying assumption behind community services is that the family, and in particular wives and daughters, will take on the role of caregivers. The family is seen implicitly as the basic institution for the

social organisation of providing care to the dependent members of society. As with policies of the past, it is not the intention of government policies to replace family care. The welfare state is 'designed to complement and enhance a particular form of the family household which provides (most of the) care and domestic services' (Kinnear and Graycar 1984:16-17). While it has not been the purpose of this thesis to discuss the gender injustice of aged care or to document the social and economic costs of providing such care, it is important to point out that family members, and in particular daughters and wives, recognize that part of their frustration with the decision to institutionalise an aged relative is due to policies not compensating them for their social and economic efforts (chapter 3). The threshold of access to services continues to focus only on the needy. The attitude that women can be counted upon to be the primary caregivers of society still prevails. Agencies often do not extend their services to clients who can rely on family or friends. This may be one reason which accounts for why the aged who live with others, for example, are less likely to receive home care services (Kendig 1986).

Domiciliary services were not seen by the respondents of this study as complementary 'caregivers' supplementing family support. Those families that used community services spoke about the poor quality and limited quantity of the programs. Looking for a long term solution, they saw only one other alternative to family care - nursing homes. For these reasons, nursing homes was their *only* solution when family care has failed. This was the result of current policies on aged care placing both aged persons and their families (as well as health professionals) in a 'no-win' situation.

Recent policy developments does however provide a hope for the future. The government's shift in the direction of public policy on care for the aged, away from institutional care and towards community based care, is welcomed by most member of the community. Enabling the aged to remain in their own homes, if they so choose, is preferrable to placing them in institutions. For this policy to succeed, the aged and their families need to have community services available as a viable option to institutional care. This may mean providing more funds to increase the quality and quantity of such services.

The Interests of Service Providers

As stated earlier in the chapter, there has been a change in the direction of government policies on aged care. The Commonwealth government has embarked on a new program that stabilises the growth of nursing home beds. In an attempt to reduce both the cost and demand for nursing home care, the government is endorsing strategies that will limit the usage of nursing home care more stringently to the more disabled members of the community. Proposals are being introduced to identify clients who really need nursing home care from those who could be cared for in the community.

Administrative controls on entry into nursing homes will restructure utilisation patterns. For instance, geriatric assessment teams reduce the extent to which nursing homes will rely on lay referrals. Directors in some cases view geriatric team assessments as providing a valuable service in evaluating clients and in referring clients to community services while they await placement. Directors are wary, however, of assessment teams assuming control over the admission decision. Such

changes may not be welcomed by the nursing home industry. In fact, directors of nursing homes claim that the government has not given much thought to the effects that this new program will have on staff morale and the quality of life of residents. The way in which directors of nursing homes perceive public policies is important because directors could have very different objectives from those stated in government policies.

Selecting residents is much more complicated than taking appropriately assessed applicant from a queue on a waiting list. Directors use informal rules to select clients. The extent to which directors can continue to select residents on the basis of these informal rules is being threatened by the introduction of geriatric assessment teams and changes in funding policies.

In their attempts to reduce the costs of delivering services, directors try to achieve a balance between high and low dependency clients. This practice, called 'the numbers game', refers to the practice of admitting a certain number of patients who consume minimal resources and take up fewer hours of nursing home care. Recent government funding policies restrict the director's flexibility to play the numbers game and leave less scope for mixing the degrees of dependency. The new residents classification system, the Care Aggregated Module (CAM), which forms the basis for determining nursing and personal care funding arrangements, is designed to compensate nursing homes for serving the most dependent clients. The government's aim is to shift the two lowest groups in the five point classification scale (the least dependent) into hostel settings. This funding scheme will force directors to take the higher dependency patients as they are the types of patients which attract the highest funds. Yet directors fear that the hours allocated to the five categories under the CAM system

will not sufficiently reward nursing homes for taking a more dependent population.

There are many who argue that the current funding scheme will eliminate the numbers game (Murphy, 1988). While this is likely to happen it will also be met with considerable resistance from directors of nursing homes. Government officials see a flaw in admitting the less disabled aged, but many directors of nursing homes do not. To them 'inappropriate placement' can be highly appropriate for some clients as well as the home. A drift towards greater dependency could well increase the demands on staff disproportionately to the increased resources. For this reason the nursing home industry is mobilising public resistance to such policy initatives. Such resistance may help to explain why overseas evidence indicates that despite government attempts to increase the proportions of very dependent people entering nursing homes, the majority of homes continue to retain a mix of residents which includes the lucid and the confused, the able and the disabled (Atkinson et al., 1986; Willcocks et al., 1987).

Differentiation between a successful and unsuccessful application depends on more than a person's level of dependency and general funding guidelines set by the government. For instance, the physical design of some homes prevents them from taking people who have mobility problems or who are prone to wandering. Levels of staffing and the organisation of daily routines restrict the number of severely disabled residents who exceed the 'tolerance' level of particular nursing homes.

The process of allocating residential placement is not a mechanistic and purely rational process, in which objective placement decisions are made on the basis of dispassionately presented facts (Mitchell and Earwicher, 1982). Rather, getting people placed involves competition within a market

framework of cost, supply and demand, in terms of the organisational needs of homes. Any watchdog committee which attempts to control nursing home placements needs to appreciate the reality behind admission decisions made by nursing home directors and why people use such services. In terms of the practicalities and demands of daily work in a nursing home, some of the current proposals cited in these reports may be difficult to translate into administrative realities. Unless the government recognizes the 'need' to allow directors of nursing homes to manage staff resources according to their own sets of priorities, or else allocates more resources to compensate for the high dependency levels, there will be resistance to compliance with current policies by those who work in nursing homes. Such conflict is partly the result of policy makers' failure to recognise why the less disabled members of the community come to rely on nursing homes, and the informal procedures directors of nursing homes use to recruit and accept residents.

Where Do We Go from Here?

The decision to seek nursing home care is not solely based on the health status of older people. Entrance into nursing homes is in fact a *socially* selective process. The question of who enters a nursing home can only be fully understood by studying the circumstances under which people choose institutional care and the meanings people give to their situation. Older people and their families differ in the ways that they define need, mobilise coping mechanisms, and are able to utilise informal and formal supports in the community. For each person a situation will be perceived, evaluated and acted or not acted upon depending on how individuals defined their situation. The theoretical focus here is to explain the processes by which people perceive their situation, and how this influences their line of

action or inaction. The decision making process, within this theoretical formulation, is not analyzed as a static event solely dependent on health and social structural factors, but as a sequence of events encompassing its own internal logic. The task of the social scientist is to recognise, analyze and utilize common elements, stages or processes among the histories of individual actions.

There remains an urgent need for further research on the social processes of institutionalisation. In order to better understand changes in people's experiences and feelings as they move from the community to the nursing home, longitudinal studies are required. Such an approach would give us not only a better understanding of the situations people find themselves in, but enable us to detect any discontinuities in people's perceptions of their situation once the move from the pre-resident to the resident phase has taken place. Future studies will also need to examine the experiences of different segments of the aged population who enter and live in nursing homes. Are there class differences in the ways people make decisions to enter and select a nursing home? Do the ethnic aged encounter similar experiences in entering and living in a nursing as do their Anglosaxon aged counterparts?

Specific attention also needs to be focussed on examining how the current restructuring of nursing homes will affect the processes by which poeple enter them. Will the shift to recruiting a more dependent population affect the quality of life of those who live and work in nursing homes? Will such a shift create a custodial model of care? The most crucial factor to be considered in all future research and policy developments is that it ought to be grounded in the realities experienced and expressed by older people.

The limitations of this study present opportunities for others to conduct further research on the topic. First, the sample included the less disabled residents of the nursing home population. Other studies need to determine whether the more disabled residents experience similar pathways into nursing homes. One can speculate that health factors for these residents played a major role in the decision to seek nursing home care. Second, the viewpoint of the health team (physician, social worker, nurse) were not included in this study. It is important for researchers to understand how health professionals interprete and perceive the situations of older people and their families, as their perceptions will play a major role in shaping older people's pathway and experiences in nursing homes. Third, this study focused largely on the micro processes influencing people's decision to seek and enter a nursing home. More attention needs to be paid to understanding how political and economic forces shape the structure and delivery of health services for the aged, and how these in turn, influence people's options.

APPENDIX A

Letter to Nursing Home

The Australian National University

The Research School of Social Sciences
Ageing and the Family Project

reference

Post Office Box 4 Canberra ACT 2600
Telegrams & Cables NATUNIV Canberra
Telex AA 62694 SOPAC
Telephone 062-49 5111

19 October 1982

Dear Matron

Thank you for attending my seminar on the 13th September at Westmead Centre and for expressing an interest in my research. Enclosed please find a copy of the research proposal presented to the Department of Community Medicine, University of Sydney.

You will remember that the purpose of the study is to collect data on two separate, but nevertheless, inter-related topics: (1) the pathway that leads to the decision to obtain nursing home care with an emphasis on the social situation from which the residents enter homes and on analyzing the quality of social relationships residents have with people; and (2) the social processes by which residents come to define their dying career. I am interesting in learning from the carers' point of view the circumstances that draw older persons to obtain formal care. The paper outlines in greater detail the theoretical concepts and research questions.

I would be very interested in learning more about your nursing home and about your role in caring for the aged. As I am attempting to obtain a first-hand account of the nursing home field from the people who are directly involved with the residents, I would like to ask you,
if you would be willing to consider the possibility of including you and your nursing home in the sample selection.

Your participation and co-operation would contribute much to the success of my research. Please let me know if you would be interested in participating in the research by filling out the enclosed form.

...2

I learned much from listening to your views at the seminar and hope that I can further discuss the topic with you. Looking forward to your reply and I hope you find the paper of interest.

Sincerely yours,

M. Victor Minichiello
PhD Student
Department of Sociology, &
Ageing Project

encl.

NURSING HOME STUDY

Ageing and the Family Project
Research School of Social Sciences
Australian National University

Please complete form and return it in the envelope provided

YOUR NAME: .....

ADDRESS: .....

.....

.....

Would it be possible to visit your nursing home sometime within the next six weeks to discuss the possibility of including you and your home in my study sample? .....

I would be grateful if you could also provide some information on your nursing home:

Are you a matron/owner, matron/manager, or employee? .....

Number of beds? .....

Number of patients? .....

Number of new admissions this year? .....

Is the nursing home a private or public establishment? .....

Comments .....

.....

.....

.....

Again, thank you for your cooperation and help.

Vic Minichiello
8 October 1982

APPENDIX B

Director of Nursing Home Interview Schedule

The interview schedule provided a working tool which generated data on relevant topic areas listed below. While the interview schedule was utilised as a guideline, the interview was not confined within its parameters. Often a number of spontanenous questions were asked to pursue a line of inquiry that arose from the interview situation. This interviewing method has been described by Taylor and Bodgan (1982) as a recursive approach.

Topic Areas:

A. Contact with Clients

Who refers them? (Doctor, social worker, geriatric team assessments, family members)

Does the nursing home belong to a referral network? Type of referral network?

Relationship of nursing home with geriatric team assessment, other nursing homes, hospitals, church, hostels?

Administrative procedures for application

Contact of director of nursing home with family members, older person

B. Method of Selecting Residents

Procedures and criteria for deciding who to select

The role of waiting list

The importance of a mix of dependent/independent ratio

The importance of resources (level of staff, physical design of home)

Who (staff member) makes the decision?

Any special considerations when selecting residents?

C. Directors views on government policies

The introduction of geriatric team assessments

Changes in the dependency ratio of the nursing home population

Community services

D. Specific information on the 90 residents selected for in-depth study

The resident's health status and social situation prior to admission

Who referred to resident to the nursing home?

The resident's level of involvement in the decision to move to the nursing home

Family support after placement

APPENDIX C

Socio-Health Questionnaire

CONFIDENTIAL

AUSTRALIAN NATIONAL UNIVERSITY

RESEARCH SCHOOL OF SOCIAL SCIENCES

AGEING AND THE FAMILY PROJECT

Preliminary Survey of the Aged in Nursing Homes

Name of Patient:

Respondent Number:

Nursing Home:

Date of Interview:

Interview Began a.m./p.m.

INTRODUCTION

Good_____, Mr/Mrs/Miss_____. I am Victor Minichiello from Ageing and the Family Project at the Australian National University. As Matron may have explained to you, I am studying older people entering and living in nursing homes. Today, I would like to talk to you about your health and family and friends. Is this alright? I would like you to know that whatever you tell me will not be repeated to anyone else. Do you have any questions?

{Record remarks from respondent}

PART 1

1. Sex
   1 Male
   2 Female

2. What is your age? _____
   (check with nursing home administrator)

3. When did you first move into a nursing home?

   _____ Month/year

   (check with nursing home administrator)

4. Where did you live just before you moved to_____
   (name of nursing home)?

   1 living alone
   2 living with others (ask questions 5-6)
   3 hospital
   4 other nursing home
   5 hostel
   6 other_____

5. (If 2 to question 4) How many people lived with you?

   _____

6. (If 2 to question 4) Could you please tell me the first names of the people who lived with you so that I know who you are talking about? How old is_____? What is _____'s relationship to you?

	First Name	Age	Relationship
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			

7. How long did you live at_____?

_____ Months

8. What is your marital status?

1 Never married
2 Married
3 Widowed (ask question 9)
4 Divorced/separated (ask question 9)

9. How long have you been widowed/divorced or separated?

_____ Months

10. If you had to name a person you feel closest to, who would that person be? (Record first name, relationship to respondent, and whether person lives in Sydney, interstate or overseas).

First Name Relationship Residence

_____

11. Do you have any children?

1 Yes (ask question 12, 13)
2 No

12. How many? _____

13. Beginning with the oldest child, could you describe each one by telling me their first names; age; where he/she lives (Sydney, interstate, overseas); how often you see him/her; how often they write to you; how often they call you on the telephone? (code: at least one a week, once or twice a month, several times a year, never)

	First Name	Age	Sex	Residence	Contact Visit/Letter/Phone
1					
2					
3					
4					

5 _____

6 _____

7 _____

8 _____

9 _____

10 _____

14. Have any relatives been in touch with you since last_____ (give day of the week)? (this includes children, spouse)

1 Yes (ask question 15)
2 No

15. Who? His/her first name? Relationship to you? Where does he/she live? (Sydney, interstate, overseas). Did you see each other, write or phone?

	Name	Relationship	Residence	Type of contact
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

16. Have any friends or neighbours been in touch with you since last_____ (give day of the week)?

1 Yes (ask question 17)
2 No

17. Who? His/her first name? Relationship to you? Where does he/she live? (Sydney, interstate, overseas). Did you see each other, write or phone?

	Name	Relationship	Residence	Type of contact
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

PART 2

I would like to ask you some questions about your health before you moved to_____ (nursing home).

18. In general, how was your health before you moved to _____ (nursing home)? Would you say that your health was:

1 Excellent
2 Good
3 Fair
4 Poor

19. Did you have any health problems just before you moved to the nursing home?

1 Yes (ask question 20)
2 No

20. What type of health problem did you have?

21. Could you tell me something about the decision to move to the nursing home? (probe to ascertain who made the decision).

PART 3 Interviewer's Observation

22. Ask nursing home administrator about the patient's ability to perform ADL upon admission.

ADL Activities:

Eat meals _____
Dress _____
Go to the toilet _____
Ambulation _____
Shower _____

1 Independent from staff
2 Assistance needed from staff
3 Fully dependent on staff

23. Resident's ability to hear conversation.

1 No difficulty
2 Some difficulty
3 Much difficulty

24. Resident's ability to communicate.

1 No difficulty
2 Some difficulty
3 Much difficulty

25. Resident's ability to comprehend questions.

1 No difficulty
2 Some difficulty
3 Much difficulty

26. Interview finished a.m./p.m.

27. General impressions.

Thank you. Can we talk again sometime?

1 Yes
2 No

APPENDIX D
In-Depth Study Questionnaire

CONFIDENTIAL

AUSTRALIAN NATIONAL UNIVERSITY

RESEARCH SCHOOL OF SOCIAL SCIENCES

AGEING AND THE FAMILY PROJECT

SURVEY OF THE AGED IN NURSING HOMES

Name of Patient

Respondent Number

Nursing Home

Date of Interview

Interview Began A.M./P.M.

INTRODUCTION

Good , Mr/Mrs/Miss . I am Victor Minichiello from Ageing and the Family Project at The Australian National University. I spoke to you in , and you said then that you would be interested in talking to me again. Can we talk today? YES (1) NO (2) (If no, record reason and try to reschedule another appointment).

As you would recall from my last visit, I am studying older people entering and living in nursing homes. The study is about people in nursing homes--how the decision was made, what life is like in a nursing home, and learning about what people feel about living in a nursing home.

Today, I would like to talk to you about what type of help you were receiving before you moved to the nursing home; your family and friends; and your decision to live in a nursing home. The interview will take a little over an hour and I may have to come back and visit you again. Do you have any questions?

Before we begin, would you mind signing a consent form, which simply gives me your permission to interview you. This procedure is required by the Canadian Fellowship Research Office, which has given me a grant to do the study. I would like to remind you that anything you say to me will be treated in the strictest confidence and that you remain free not to answer any questions you prefer to exclude.

I would also like to ask your permission to tape the interview so that I don't have to worry about taking notes while I listen to you. Is this alright? YES (1) NO (2) (If no, record reason).

Thank you, Mr/Mrs/Miss , can we begin.

PART 1

A. I WOULD LIKE TO BEGIN BY YOU TELLING ME SOMETHING ABOUT WHERE YOU LIVED FOR MOST OF YOUR LIFE AND HOW YOU CAME TO LIVE IN A NURSING HOME (PROBE TO DETERMINE THE RESIDENTIAL PATHWAY INTO THE NURSING HOME)?

B. I AM GOING TO ASK SOME QUESTIONS ABOUT HOW WELL YOU WERE ABLE TO GET ALONG WHEN YOU WERE LIVING AT HOME, , THAT IS DURING THE LAST MONTH BEFORE YOU MOVED TO .

I WILL SHOW YOU CARDS ABOUT SOME THINGS WHICH QUITE A FEW PEOPLE HAVE DIFFICULTY IN DOING WITHOUT HELP. FOR EACH CARD, I'D LIKE YOU TO TELL ME WHETHER YOU WERE ABLE TO DO THAT

WITHOUT ANY DIFFICULTY (1)

ON YOUR OWN WITH DIFFICULTY (2)

ONLY WITH HELP (3)

OR NOT AT ALL (4)

*IF PATIENT ANSWERS THAT HE/SHE WAS ABLE TO MANAGE ALONE (RESPONSE 1 OR 2), THEN ASK: DID YOU USE ANY MECHANICAL AID OR DEVICE TO HELP YOU?

*IF PATIENT ANSWERS THAT HE/SHE NEEDED ASSISTANCE (RESPONSE 3), THEN ASK: DID YOU NEED A LOT OF HELP, ONLY A LITTLE HELP, OR DID YOU NEED SOMEONE TO KEEP AN EYE ON YOU TO BE SURE YOU WERE ALRIGHT?

CODE

IF RESPONSE 1 + AID (5)

IF RESPONSE 2 + AID (6)

IF RESPONSE 3 + LOT OF HELP (7)

IF RESPONSE 3 + LITTLE HELP (8)

IF RESPONSE 3 + SUPERVISION ONLY (9)

don't know/not sure (88)

refusal (99)

DURING THE LAST MONTH WHEN YOU WERE LIVING AT ,

WERE YOU ABLE TO... (SHOW CARDS)

*a. ...get around the house or flat...

*b. ...get up and down the steps and stairs...

*c. ...go out of the house on your own...

*d. ...walk half a mile...

*e. ...ride in a car, as a passenger...

*f. ...use public transport...

*g. ...get on and off a chair...

*h. ...get in and out of bed...

*i. ...use the toilet...

*j. ...cut your toenails...

*k. ...take a bath or shower...

*l. ...dress yourself...

*m. ...eat meals...

*n. ...prepare meals...

*o. ...use the telephone...

*p. ...shop for food or errands...

*q. ...clean the house or flat...

*r. ...do minor house repairs like changing light bulbs or fuses

B. NOW, I AM GOING TO SHOW YOU AGAIN A LIST OF CARDS WITH PERSONAL CARE AND HOUSEHOLD TASKS. I WOULD LIKE YOU TO TELL ME WHO DID MOST OF THE MENTIONED ACTIVITY JUST ONE MONTH BEFORE YOU MOVED TO .

DURING THE LAST MONTH YOU WERE LIVING AT HOME, WHO DID MOST OF THE...(RECORD FIRST NAME AND RELATIONSHIP).

DID ANYONE ELSE DO SOME OF THE...? IF YES, WHO WAS THAT? (RECORD FIRST NAME AND RELATIONSHIP).

1. SHOPPING AND ERRANDS

most

some

2. MEALS PREPARATION

most

some

3. HOUSEWORK

most

some

(IF HAS HELP WITH MEALS)

4. HOW MANY MEALS A WEEK WERE PREPARED FOR YOU?

5. ABOUT HOW LONG DID YOU HAVE HELP WITH THE MEALS?

If more than a year... years

If less than a year... months

6. ABOUT HOW MANY HOURS A WEEK DID YOU GET HELP WITH THE HOUSEWORK?

7. ABOUT HOW LONG DID YOU HAVE HELP WITH THE HOUSEWORK?

If more than a year... years

If less than a year... months

8. IS THERE ANYTHING YOU DIDN'T PARTICULARLY LIKE ABOUT THE HELP YOU RECEIVED WITH THE MEALS/HOUSEWORK?

Yes 1

No 2

don't know/not sure 88

9. (IF YES) WHAT DIDN'T YOU LIKE?

	source of help	reason unsatisfactory
1.		
2.		
3.		

C. OVER THE LAST YEAR WHEN YOU WERE LIVING AT HOME, WHO DID MOST OF THE...?

DID ANYONE ELSE DO SOME OF THE...? WHO?

1. GARDENING

most

some

not applicable (no garden)

2. MINOR HOUSE REPAIRS LIKE CHANGING LIGHT BULBS OR FUSES

most

some

3. MAJOR HOUSE REPAIRS LIKE FIXING A BROKEN TILE, PAINTING ETC..

most

some

D. NOW, I WANT YOU TO TELL ME IF ANYONE HELPED YOU WITH ANY OF THE FOLLOWING ACTIVITIES DURING THE LAST MONTH WHEN YOU WERE LIVING AT .

1. DID ANYONE...? (Show cards) ANYONE ELSE? (RECORD FIRST NAME AND RELATIONSHIP). YES (1) NO (2)

2. HOW OFTEN DID HE/SHE HELP YOU WITH ? WOULD YOU SAY

Daily (1)

Several times a week (2)

About once a week (3)

Several times a month (4)

About once a month (5)

Never/Not applicable (6)

3. ABOUT HOW LONG DID HELP YOU WITH ? (RECORD REPORTED TIME)

ACTIVITY	RECEIVED?	HOW OFTEN	HOW LONG?
*a. Accompany you to the doctor/dentist			
*b. Help you manage your financial affairs like paying bills			
*c. Help with your medication			
*d. Help you with personal care like dressing			
*e. Drive you to places			
*f. Give you money to pay bills			

E. I WOULD LIKE TO KNOW MORE ABOUT WHO HELPED YOU WITH PERSONAL CARE AND HOUSEHOLD TASKS BEFORE YOU MOVED AWAY FROM HOME AND CAME TO LIVE AT

.

1. WERE YOU RECEIVING ANY HELP FROM THE FOLLOWING GOVERNMENT OR COMMUNITY

AGENCIES ONE MONTH BEFORE YOU MOVED TO ? YES (1) NO (2)

2. WAS ANYONE ELSE IN THE HOUSE RECEIVING ? WHO? (RECORD NAME AND RELATIONSHIP). YES (1) NO (2)

3. (IF RECEIVING SERVICE) HOW OFTEN WERE YOU RECEIVING ? WOULD YOU SAY

Daily (1)

Several times a week (2)

Once a week (3)

Once or twice a fortnight (4)

Once or twice a month (5)

Less often than once a month (6)

Never (7)

4. ABOUT HOW LONG DID YOU RECEIVE ? (RECORD REPORTED TIME)

SERVICES	RECEIVED?	ANYONE ELSE?	HOW OFTEN?	HOW LONG
*a. Meals on Wheels				
*b. Home Help Services (e.g., cleaning, laundry, shopping, gardening)				
*c. Home Nursing				
*d. Domiciliary Service Care Benefit to Relative				
*e. Private Paid Help				

*f. Day Centre

*g. Physiotherapy

*h. Did you visit the
Doctor

*i. Other (Specify)

5. (IF PERSON WAS NOT RECEIVING SERVICES) WHY DIDN'T YOU USE ANY OF THE GOVERNMENT OR COMMUNITY SERVICES?

F. FINALLY, I WOULD LIKE YOU TO TELL ME ABOUT THE SUPPORT YOU WERE RECEIVING WHEN YOU WERE LIVING AT .

1. DID ANY FAMILY MEMBERS OFFER YOU ANY KIND OF HELP THAT YOU DID NOT ACCEPT?
YES (1) NO (2)

2. WHO? (RECORD FIRST NAME AND RELATIONSHIP) ANYONE ELSE?

1.

2.

3.

4.

5.

3. WHAT KIND OF HELP DID OFFER YOU THAT YOU DID NOT ACCEPT?

4. WHY DIDN'T YOU ACCEPT 'S HELP?

5. DID ANY OF YOUR FRIENDS AND/OR NEIGHBOURS OFFER YOU ANY TYPE OF HELP THAT YOU DID NOT ACCEPT? YES (1) NO (2)

6. WHO? (RECORD FIRST NAME AND RELATIONSHIP) ANYONE ELSE?

1.

2.

3.

4.

5.

7. WHAT TYPE OF HELP DID OFFER YOU THAT YOU DID NOT ACCEPT?

8. WHY DIDN'T YOU ACCEPT 'S HELP?

9. LOOKING BACK, DO YOU FEEL YOUR FAMILY HELPED YOU AS MUCH AS YOU NEEDED? YES (1) NO (2) NOT APPLICABLE/NO FAMILY (3) WHY?

10. (IF YES OR NO) IN WHAT OTHER WAY COULD THEY HAVE HELPED YOU TO REMAIN AT HOME?

11. WHY DO YOU THINK THEY DIDN'T OFFER YOU THE TYPE OF HELP YOU NEEDED?

12. WHY DIDN'T YOU ASK YOUR FAMILY FOR THIS TYPE OF HELP?

13. WHEN YOU MOVED TO THE NURSING HOME, DID YOUR FAMILY HAVE ANY PROBLEMS, SUCH AS ILLNESS OR DEATH OF A FAMILY MEMBER, OR FINANCIAL PROBLEMS? YES (1) NO (2)

14. WHAT KINDS OF PROBLEMS?

1.

2.

3.

4.

5.

15. DID THESE PROBLEMS AFFECT THEIR ABILITY TO HELP YOU? YES (1) NO (2)

16. WHY?

17. NOW, WHAT ABOUT YOUR FRIENDS AND/OR NEIGHBOURS, WHAT OTHER THINGS COULD THEY HAVE REASONABLY DONE FOR YOU TO HELP?

1.

2.

3.

4.

5.

18. WHAT DO YOU THINK PREVENTED THEM FROM DOING THESE THINGS?

19. WHY DIDN'T YOU ASK YOUR FRIENDS OR NEIGHBOURS FOR THIS TYPE OF HELP?

20. WHAT ABOUT GOVERNMENT OR COMMUNITY AGENCIES, WHAT OTHER THINGS COULD THEY HAVE DONE FOR YOU TO HELP?

PART II

A. I WOULD BE VERY INTERESTED IN KNOWING MORE ABOUT YOUR DECISION TO MOVE TO

1. WHEN DID YOU FIRST THINK ABOUT COMING TO LIVE IN A NURSING HOME? (RECORD DATE)

2. WHY DID YOU CONSIDER SUCH A MOVE?

3. (IF PATIENT DID NOT ENTER NURSING HOME WHEN HE/SHE FIRST CONSIDERED THE POSSIBILITY ASK) WHY WAS THIS PLAN NOT CARRIED OUT AT THE TIME?

4. IF YOU HAD TO MENTION THE THREE MOST IMPORTANT REASONS FOR YOU MOVING TO A NURSING HOME, WHAT WOULD THEY BE:

1.

2.

3.

5. (FOR EACH REASON MENTIONED ASK) WHY DO YOU THINK THIS WAS AN IMPORTANT REASON?

1.

2.

3.

6. WHY WAS THE APPLICATION MADE AT THAT PARTICULAR TIME AND NOT BEFORE? DID ANYTHING IN PARTICULAR HAPPEN WHICH PROMPTED THE DECISION?

B. COULD WE NOW TALK ABOUT YOUR APPLICATION TO THIS NURSING HOME AND WHY YOU DECIDED TO COME AT .

1. WHO TOLD YOU ABOUT . (RECORD FIRST NAME AND RELATIONSHIP)

1.

2.

3.

2. WHO FIRST CONTACTED THE MATRON? (RECORD FIRST NAME AND RELATIONSHIP)

1.

2.

3.

3. WHAT HAPPENED NEXT AFTER THE MATRON WAS CONTACTED?

4. WHO FILLED OUT THE FORMS AT THE NURSING HOME?

1.

2.

3.

5. DID YOU APPLY TO ANY OTHER PLACES, OTHER THAN ? YES (1) NO (2)

6. (IF YES) TO WHICH OTHER PLACES DID YOU APPLY? (ENTER NAMES OF INSTITUTIONS).

1.

2.

3.

4.

5.

7. WERE YOU ON 'S WAITING LIST? YES (1) NO (2)

8. (IF YES) FOR HOW LONG? (RECORD TIME)

9. WERE YOU ON ANY OTHER NURSING HOMES' WAITING LISTS? YES (1) NO (2)

10. (IF YES) WHICH NURSING HOMES? (RECORD NAME OF INSTITUTION)

1.

2.

3.

4.

5.

11. WHY DID YOU CHOOSE TO LIVE AT ?

12. DID YOU VISIT THE NURSING HOME BEFORE YOU MOVED HERE? YES (1) NO (2)

13. (IF YES) WITH WHOM? (RECORD FIRST NAME AND RELATIONSHIP)

1.

2.

3.

4.

5.

14. (IF NO) WHY DIDN'T YOU VISIT THE NURSING HOME?

C. A NUMBER OF DIFFERENT INDIVIDUALS ARE OFTEN INVOLVED IN HELPING A PERSON TO MAKE THE DECISION TO MOVE INTO A NURSING HOME.

1. WHO FIRST SUGGESTED MOVING TO ? (RECORD FIRST NAME)

   1.

   2.

2. WHAT OTHER PEOPLE INFLUENCED YOUR DECISION? (RECORD NAME AND RELATIONSHIP)

   1.

   2.

   3.

   4.

   5.

3. ANYONE ELSE?

4. WHO WOULD YOU SAY WAS MOST INVOLVED IN MAKING THE DECISION? (RECORD FIRST NAME AND RELATIONSHIP)

   1.

   2.

5. (IF SELF TO Q.4 THEN SKIP Q.5, 6 AND 7) HOW MUCH OF A SAY DID YOU HAVE IN MAKING THE DECISION? WERE YOU INVOLVED

   VERY MUCH (1)

   A MODERATE AMOUNT (2)

   VERY LITTLE OR NOT AT ALL (3)

6. (IF PATIENTS ANSWERS 3 TO Q.5) WHY DIDN'T YOU HAVE MORE OF A SAY?

7. HOW DID YOU FEEL ABOUT THIS?

D. I WOULD LIKE TO KNOW MORE ABOUT HOW YOU FEEL ABOUT LIVING IN A NURSING HOME.

1. WHAT ONE WORD WOULD YOU SAY BEST DESCRIBES YOUR FEELINGS ABOUT HAVING TO MOVE INTO A NURSING HOME? WHY IS THAT?

2. WHAT DID YOU THINK ABOUT MOVING HERE? JUST PRIOR TO

3. HOW DO YOU FEEL ABOUT LIVING HERE NOW?

4. HAS YOUR WAY OF LIFE CHANGED MUCH SINCE YOU MOVED HERE? YES (2) NO (1)

5. (IF YES) IN WHAT WAY?

6. COULD YOU DESCRIBE TO ME WHAT IT IS LIKE TO LIVE HERE? WHAT WOULD YOU TELL A FRIEND OF YOURS WHO WAS THINKING OF MOVING TO A NURSING HOME?

7. IS LIVING HERE WHAT YOU EXPECTED? WHY?

8. WHAT DID YOU THINK ABOUT MOVING TO A NURSING HOME. WERE YOU

VERY MUCH IN FAVOUR OF THE MOVE (1)

SOMEWHAT IN FAVOUR OF THE MOVE (2)

NEUTRAL (3)

SOMEWHAT OPPOSED TO THE MOVE (4)

VERY MUCH OPPOSED TO THE MOVE (5)

9. WHY?

10. WHAT ADVANTAGES DO YOU SEE IN HAVING MOVED TO THE NURSING HOME?

11. WHAT DISADVANTAGES?

12. WHAT ABOUT YOUR FAMILY, WHAT DID THEY GENERALLY THINK ABOUT YOU MOVING TO THE NURSING HOME? WERE THEY

VERY MUCH IN FAVOUR (1)

SOMEWHAT IN FAVOUR (2)

NEUTRAL (3)

SOMEWHAT OPPOSED (4)

VERY MUCH OPPOSED (5)

13. WHY?

14. WHAT THINGS ABOUT LIVING HERE DO YOU LIKE?

15. WHAT THINGS ABOUT LIVING HERE DON'T YOU LIKE?

16. WOULD YOU HAVE PREFERRED MOVING TO SOMEWHERE ELSE? YES (1) NO (2)

17. WHERE? WHY?

18. ARE YOU TRYING TO FIND SOMEWHERE ELSE TO LIVE? YES (1) NO (2)

19. (IF YES) WHAT?

PART III

A. THE NEXT FEW QUESTIONS ARE ABOUT THE PEOPLE WHO YOU FEEL CLOSE TO.

1. IS THERE ANYONE TO WHOM YOU FEEL QUITE CLOSE? YES (1) NO (2)

2. IN ANSWERING THE QUESTIONS, YOU CAN SAY NOBODY OR SEVERAL PEOPLE; YOU CAN ALSO REPEAT PEOPLE--IT JUST DEPENDS ON WHAT YOU THINK. IS THERE SOMEONE YOU CONFIDE IN ABOUT THINGS THAT ARE IMPORTANT TO YOU? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

WHO IS THAT? IS THERE ANYONE ELSE? (RECORD FIRST NAME/RELATIONSHIP).

3. IS THERE SOMEONE WHO KNOWS YOU VERY WELL AS A PERSON, AND ACCEPTS YOU JUST AS YOU ARE? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

WHO IS THAT? IS THERE ANYONE ELSE? (RECORD FIRST NAME/RELATIONSHIP)

4. IS THERE SOMEONE WHO MAKES YOU FEEL NEEDED AND APPRECIATED? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

WHO IS THAT? IS THERE ANYONE ELSE? (RECORD FIRST NAME/RELATIONSHIP)

5. IS THERE SOMEONE WITH WHOM YOU ENJOY COMMON INTERESTS OR ACTIVITIES? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

WHO IS THAT? IS THERE ANYONE ELSE? (RECORD FIRST NAME/RELATIONSHIP)

6. IS THERE ANYONE ELSE WHOM YOU HAVEN'T MENTIONED WHO YOU FEEL VERY CLOSE TO? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

WHO IS THAT? IS THERE ANYONE ELSE? (RECORD FIRST NAME/RELATIONSHIP)

7. OF THESE PEOPLE WE'VE BEEN TALKING ABOUT, WHO ARE YOU CLOSEST TO?

1.

2.

8. SINCE YOU MOVED HERE, HAVE YOU LOST CONTACT WITH ANYONE VERY CLOSE TO YOU--THROUGH THINGS LIKE DEATH OR PEOPLE MOVING AWAY FROM SYDNEY? YES (1) NO (2) NOT SURE/DON'T KNOW (3)

9. (IF YES) WHO WAS THAT AND WHAT HAPPENED? (RECORD FIRST NAME/RELATIONSHIP AND REASON LOST CONTACT)

	RELATIONSHIP	REASON LOST CONTACT
1.		
2.		
3.		
4.		
5.		

PART IV

A. I WOULD LIKE TO KNOW WHETHER YOU HAVE HAD ANY VISITORS IN THE LAST WEEK.

1. HAS ANYONE COME TO VISIT YOU SINCE LAST ? (GIVE DAY OF THE WEEK). YES (1) NO (2) (IF NO, GO TO QUESTION 5)

2. (IF YES) WHO WAS THAT? (RECORD FIRST NAME AND RELATIONSHIP)

3. HOW MANY TIMES DID COME?

NAME	RELATIONSHIP	NO OF TIMES

4. HOW MANY TIMES DID YOU HAVE VISITORS LAST WEEK? (if more than 5, an estimate is acceptable)

5. IN THE PAST WEEK, HAVE YOU SEEN MORE OF PEOPLE THAN YOU USUALY DO, ABOUT THE SAME, OR LESS THAN YOU USUALLY DO? (do not include people at nursing home)

MORE (1)

ABOUT THE SAME (2)

LESS (3)

DON'T KNOW/NOT SURE (8)

6. THINK BACK TO BEFORE YOU MOVED TO THE NURSING HOME, DO YOU SEE PEOPLE MORE THAN, ABOUT THE SAME, OR LESS NOW? (do not include people at nursing home)

MORE NOW (1)

ABOUT THE SAME (2)

LESS THAN (3)

DON'T KNOW/NOT SURE (8)

7. HAVE YOU RECEIVED ANY LETTERS IN THE LAST WEEK? YES (1) NO (2) DON'T KNOW/NOT SURE (8)

8. WHO FROM? (RELATIONSHIP AND FIRST NAME)

1.

2.

3.

9. DID YOU TALK TO ANYONE ON THE PHONE YESTERDAY? YES (1) NO (2) DON'T KNOW/NOT SURE

10. WHO?

1.

2.

3.

B. NOW, I WOULD LIKE TO LEARN MORE ABOUT YOUR FAMILY. (USE MATRIX SHEET)

1. I'D LIKE TO BEGIN BY ASKING YOU IF YOU HAVE ANY CHILDREN? YES (1) NO (2)

2. HOW MANY?

3. BEGINNING WITH THE OLDEST CHILD, COULD YOU TELL ME THEIR FIRST NAMES? (COMPLETE MATRIX QUESTIONS FOR EACH PERSON)

4. (IF MARRIED) IS YOUR WIFE/HUSBAND STILL LIVING? YES (1) NO (2) (IF YES) WHAT IS HIS/HER NAME? (COMPLETE MATRIX QUESTIONS)

5. DO YOU HAVE ANY BROTHERS OR SISTERS? YES (1) NO (2)

6. HOW MANY LIVING BROTHERS AND/OR SISTERS DO YOU HAVE?

7. BEGINNING WITH YOUR OLDEST LIVING BROTHER OR SISTER, COULD YOU TELL ME THEIR FIRST NAMES? (COMPLETE MATRIX QUESTIONS)

8. NOW, COULD YOU TELL ME THE FIRST NAMES OF THOSE RELATIVES (e.g., COUSINS, NIECES, NEPHEWS, GRANDCHILDREN, AUNTS, UNCLES) YOU FEEL CLOSE TO? (COMPLETE MATRIX QUESTIONS)

9. THE FIRST NAMES OF FRIENDS OR PEOPLE IN THE NURSING HOME YOU FEEL CLOSE TO? YES (1) NO (2) (COMPLETE MATRIX QUESTIONS) (SPECIFY IF FRIENDS ARE ALSO RESIDENTS)

<u>MATRIX QUESTIONS FOR EACH PERSON NAMED</u>

1. WHERE DOES HE/SHE LIVE?

SAME NEIGHBOURHOOD (1)

IN SYDNEY, WITHIN 5 TO 10 MILES OF NURSING HOME (2)

IN SYDNEY, WITHIN 11 TO 15 MILES OF NURSING HOME (3)

IN SYDNEY, OVER 16 MILES OF NURSING HOME (4)

NEW SOUTH WALES (5)

INTERSTATE (6)

OVERSEAS (7)

DON'T KNOW (8)

2. SEX?

MALE (1)

FEMALE (2)

3. MARITAL STATUS?

MARRIED (1)

DE FACTO (2)

WIDOWED (3)

SEPARATED (4)

DIVORCED (5)

DON'T KNOW (8)

4. ABOUT HOW OLD IS.....?

UNDER 13 (1)

TEENS (2)

TWENTIES (3)

THIRTIES (4)

FORTIES (5)

FIFTIES (6)

SIXTIES (7)

70 OR MORE (9)

DON'T KNOW (8)

5. DOES HE/SHE HAVE A FULL-TIME JOB, PART-TIME JOB, OR NOT WORKING?

FULL-TIME (1)

PART-TIME (2)

NOT WORKING (3)

DON'T KNOW (8)

6. ABOUT HOW OFTEN DO YOU USUALLY SEE.....?

DAILY (1)

SEVERAL TIMES A WEEK (2)

ONCE A WEEK (3)

ONCE OR TWICE A MONTH (4)

SEVERAL TIMES A YEAR (5)

EVERY YEAR OR SO (6)

NOT IN THE LAST TWO YEARS (7)

DON'T KNOW (8)

7. HOW OFTEN DO YOU USUALLY TALK TO .....ON THE PHONE?

DAILY (1)

SEVERAL TIMES A WEEK (2)

ONCE A WEEK (3)

ONCE OR TWICE A MONTH (4)

SEVERAL TIMES A YEAR (5)

EVERY YEAR OR SO (6)

DON'T TALK ON THE PHONE (7)

DON'T KNOW (8)

8. HOW OFTEN DOES HE/SHE USUALLY SEND YOU A LETTER?

DAILY (1)

SEVERAL TIMES A WEEK (2)

ONCE A WEEK (3)

ONCE OR TWICE A MONTH (4)

SEVERAL TIMES A YEAR (5)

EVERY YEAR OR SO (6)

DON'T WRITE TO EACH OTHER (7)

DON'T KNOW (8)

9. COULD YOU TELL ME SOMETHING MORE ABOUT....., AND HOW YOU GET ON WITH HIM/HER?

POSITIVE RELATIONSHIP (1)

NEUTRAL (2)

NEGATIVE RELATIONSHIP (3)

10. SINCE YOU MOVED HERE, HOW HELPFUL/SUPPORTIVE HAS....., BEEN IN HELPING YOU ADJUST TO LIVING HERE?

VERY HELPFUL (1)

SOMEWHAT HELPFUL (2)

NOT VERY HELPFUL (3)

NOT VERY HELPFUL AT ALL (4)

DON'T KNOW (8)

11. (IF 1,2 TO Q 10) IN WHAT WAY HAS .....BEEN HELPFUL/SUPPORTIVE?

12. DO YOU FEEL YOU SEE .....AS OFTEN AS YOU LIKE SINCE YOU HAVE MOVED HERE? DO YOU THINK YOU SEE .....MORE THAN, ABOUT THE SAME, OR LESS THAN WHAT YOU DID BEFORE YOU MOVED HERE?

MORE THAN (1)

ABOUT THE SAME (2)

LESS THAN (3)

DON'T KNOW (8)

C. 1. IN GENERAL, WOULD YOU SAY YOUR FAMILY IS VERY CLOSE TO YOU? YES (1) NO (2)

2. WHY?

3. IS THERE ANYONE IN THE FAMILY YOU HAVE MUCH DIFFICULTY GETTING ALONG WITH? YES (1) NO (2)

4. WHO? (RECORD FIRST NAME AND RELATIONSHIP) ANYONE ELSE? WHY?

1.

2.

3.

5. DO YOU THINK MOVING TO THE NURSING HOME HAS CHANGED YOUR RELATIONSHIP WITH YOUR FAMILY? YES (1) NO (2)

6. HOW?

7. HAS IT CHANGED WITH ANYONE IN PARTICULAR? YES (1) NO (2)

8. (IF YES) WHO? (RECORD FIRST NAME AND RELATIONSHIP) WHY?

1.

2.

9. WHAT ABOUT FRIENDS? HAS MOVING HERE CHANGED YOUR RELATIONSHIP WITH THEM? YES (1) NO (2)

10. WHY?

11. ANY FRIEND IN PARTICULAR? YES (1) NO (2)

12. (IF YES) WHO? (RECORD FIRST NAME AND RELATIONSHIP)

1.

2.

PART V

NOW, I'M GOING TO ASK YOU HOW YOU FEEL ABOUT SOME THINGS IN YOUR LIFE TODAY. FIRST, I'LL READ A STATEMENT, AND THEN I'D LIKE YOU TO TELL ME WHETHER YOU AGREE OR DISAGREE.

CODES

(1) AGREE

(2) DISAGREE

(8) DON'T KNOW/NOT SURE

*a. I am as happy now as when I was younger.

*b. Life is hard for me much of the time.

*c. I get angry more than I use to.

*d. I have a lot to be sad about.

*e. I sometimes worry so much that I can't sleep.

*f. I have as much enery as I had last year.

*g. Little things bother me more this year.

*h. I am afraid of a lot of things.

*i. Things keep getting worse as I get older.

*j. If something bad happens, I take it hard.

*k. I sometimes feel that life isn't worth living.

*l. I get upset easily.

*m. As you get older, you are less useful.

2. NOW, AS YOU GET OLDER, WOULD YOU SAY THAT THINGS ARE BETTER OR WORSE THAN YOU THOUGHT THEY WOULD BE?

BETTER (1)

WORSE (2)

SAME (3)

DON'T KNOW/NOT SURE (8)

3. TAKING THINGS ALTOGETHER, HOW WOULD YOU SAY THINGS ARE THESE DAYS? WOULD YOU SAY THAT YOU'RE...

VERY HAPPY (1)

FAIRLY HAPPY (2)

NOT TOO HAPPY (3)

DON'T KNOW/NOT SURE (8)

4. HOW SATISFIED ARE YOU WITH YOUR LIFE AS A WHOLE THESE DAYS? WOULD YOU SAY THAT YOU'RE...

VERY SATISFIED (1)

SATISFIED (2)

SOMEWHAT SATISFIED (3)

NOT VERY SATISFIED (4)

DON'T KNOW/NOT SURE (8)

5. WHAT WOULD YOU SAY ARE THE WORST THINGS ABOUT BEING OLDER THAN 65?

1.

2.

3.

4.

6. WHAT WOULD YOU SAY ARE THE BEST THINGS ABOUT BEING OLDER THAN 65?

1.

2.

3.

4.

PART VI

A. I WOULD LIKE TO KNOW A LITTLE MORE ABOUT YOU.

1. IN WHAT COUNTRY WERE YOU BORN?

AUSTRALIA (1)

NEW ZEALAND (2)

BRITAIN OR IRELAND (3)

ITALY (4)

GREECE OR CYPRUS (5)

YUGOSLAVIA (6)

POLAND, CZECHOSLAVAKIA, HUNGARY, ROMANIA (7)

BULGARIA, LATVIA, ESTONIA, LITHUNIA, UKRAINE, USSR (8)

GERMANY (9)

NETHERLANDS (10)

PORTUGAL, SPAIN, MALTA (11)

MEXICO, SOUTH AMERICA (12)

CANADA, USA (13)

AFRICA (14)

OTHER.....(15)

DON'T KNOW (16)

2. (IF NOT BORN IN AUSTRALIA) APROXIMATELY WHEN DID YOU FIRST COME TO AUSTRALIA TO LIVE?

1980s (1)

1970s (2)

1960s (3)

1950s (4)

1940s (5)

EARLIER (6)

DON'T KNOW/NOT SURE (7)

3. WHAT IS THE HIGHEST GRADE YOU COMPLETED IN PRIMARY OR HIGH (SECONDARY) SCHOOL?

4. HAVE YOU HAD ANY ADDITIONAL FORMAL EDUCATION AT A COLLEGE, UNIVERSITY OR TECHNICAL SCHOOL? (IF YES) WHAT KIND OF TRAINING WAS THAT?

UNIVERSITY: NUMBER OF YEARS

DEGREES

TECHNICAL: TYPE

NUMBER OF YEARS

DIPLOMAS

5. APPROXIMATELY WHEN WAS THE LAST TIME YOU WORKED AT A PAYING JOB? (YEAR)

6. WHAT KIND OF A JOB WAS THAT? (BE SPECIFIC)

7. HOW LONG WERE YOU EMPLOYED AT THAT TYPE OF WORK? (YEARS)

8. WHY DID YOU STOP WORKING?

COMPULSORY RETIREMENT (1)

ELIGIBLE FOR RETIREMENT AT FULL PENSION (2)

HAD TO QUIT DUE TO HEALTH (3)

PERSONAL REASONS OTHER THAN HEALTH (4)

LAID OFF (5)

OTHER (6)

DON'T KNOW (7)

9. WHAT KIND OF WORK DID YOU DO THROUGHOUT MOST OF YOUR WORKING LIFE?

SAME AS ABOVE (1)

OTHER (SPECIFY.....) (2)

10. (IF EVER-MARRIED FEMALE) WHAT WAS THE OCCUPATION OF YOUR HUSBAND?

11. DO YOU OWN A HOUSE OR FLAT? YES (1) NO (2)

12. DID YOU EVER OWN A HOUSE OR FLAT? YES (1) NO (2) (IF YES, WHAT HAPPENED TO IT?)

13. NOW I WOULD LIKE TO ASK ABOUT HOW THINGS ARE FOR YOU NOW. COULD YOU TELL

5. APPROXIMATELY WHEN WAS THE LAST TIME YOU WORKED AT A PAYING JOB? (YEAR)

6. WHAT KIND OF A JOB WAS THAT? (BE SPECIFIC)

7. HOW LONG WERE YOU EMPLOYED AT THAT TYPE OF WORK? (YEARS)

8. WHY DID YOU STOP WORKING?

COMPULSORY RETIREMENT (1)

ELIGIBLE FOR RETIREMENT AT FULL PENSION (2)

HAD TO QUIT DUE TO HEALTH (3)

PERSONAL REASONS OTHER THAN HEALTH (4)

LAID OFF (5)

OTHER (6)

DON'T KNOW (7)

9. WHAT KIND OF WORK DID YOU DO THROUGHOUT MOST OF YOUR WORKING LIFE?

SAME AS ABOVE (1)

OTHER (SPECIFY.....) (2)

10. (IF EVER-MARRIED FEMALE) WHAT WAS THE OCCUPATION OF YOUR HUSBAND?

11. DO YOU OWN A HOUSE OR FLAT? YES (1) NO (2)

12. DID YOU EVER OWN A HOUSE OR FLAT? YES (1) NO (2) (IF YES, WHAT HAPPENED TO IT?)

13. NOW I WOULD LIKE TO ASK ABOUT HOW THINGS ARE FOR YOU NOW. COULD YOU TELL

ME WHETHER YOU ARE NOW ABLE TO DO THE FOLLOWING ACTIVITIES

WITHOUT ANY DIFFICULTY (1)

ON YOUR OWN WITH DIFFICULTY (2)

ONLY WITH HELP (3)

OR NOT AT ALL (4)

DON'T KNOW/NOT SURE (5)

ARE YOU ABLE TO (SHOW CARDS)...

*a. ...get around the nursing home...

*b. ...get up and down the steps and stairs...

*c. ...go out of the nursing home...

*d. ...walk in the neighbourhood...

*e. ...ride in a car, as a passenger...

*f. ...get on and off a chair...

*g. ...get in and out of bed...

*h. ...use the toilet...

*i. ...use the telephone...

*j. ...take a bath or shower...

*k. ...dress yourself...

*l. ...cut your toenails...

*m. ...eat meals...

*n. ...write letters...

*o. ...read letters...

14. NOW, I'D LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR HEALTH. WOULD YOU SAY YOUR OVERALL HEALTH IS...

EXCELLENT (1)

GOOD (2)

FAIR (3)

POOR (4)

15. WOULD YOU SAY YOUR EYESIGHT (WITH GLASSES) IS...

GOOD (1)

FAIR (2)

POOR (3)

BLIND (4)

16. WOULD YOU SAY YOUR HEARING (WITH AID) IS...

GOOD (1)

FAIR (2)

POOR (3)

DEAF (4)

17. AND DO YOU HAVE ANY PROBLEMS WITH YOUR FEET THAT MAKES WALKING PAINFUL OR DIFFICULT?

NO PROBLEMS (1)

SOME PROBLEMS (2)

A LOT OF PROBLEMS (3)

DON'T KNOW/NOT SURE (4)

18. WOULD YOU SAY YOUR HEALTH IS BETTER, ABOUT THE SAME, OR NOT AS GOOD AS MOST PEOPLE YOUR AGE?

BETTER (1)

SAME (2)

NOT AS GOOD (3)

19. IS YOUR HEALTH NOW BETTER, ABOUT THE SAME, OR NOT AS GOOD AS IT WAS JUST BEFORE YOU MOVED TO THE NURSING HOME?

BETTER NOW (1)

ABOUT THE SAME (2)

NOT AS GOOD NOW (3)

DON'T KNOW/NOT SURE (8)

20. DID YOU HAVE A SERIOUS ILLNESS OR ACCIDENT BEFORE YOU MOVED TO THE NURSING HOME? YES (1) NO (2)

21. (IF YES) WHAT?

22. WERE YOU EVER IN A HOSPITAL? YES (1) NO (2)

23. WHEN? WHY?

B. IS THERE A FRIEND AND/OR RELATIVE THAT ASSISTED YOU IN LOOKING FOR A NURSING HOME, THAT I CAN CONTACT TO OBTAIN HIS/HER OPINION? YES (1) NO (2)

(IF YES) WHO WOULD YOU SUGGEST IS THE MOST APPROPRIATE PERSON I CONTACT?

(RECORD FULL NAME, RELATIONSHIP AND ADDRESS)

NAME	RELATIONSHIP	ADDRESS

PART VII

INTERVIEWER OBSERVATIONS

1. INTERVIEW FINISHED? A.M./P.M.

2. INTERRUPTIONS (RECORD TIME AND WHY)

	TIME	WHY?
1.		
2.		
3.		
4.		

5.

3. WERE OTHERS PRESENT DURING THE INTERVIEW?

YES (1)

NO (2)

4. SPECIFY RELATIONSHIP TO RESPONDENT AND WHETHER IT AFFECTED THE INTERVIEW.

RELATIONSHIP EFFECT

1.

2.

3.

4.

5.

5. DID RESPONDENT TIRE DURING THE INTERVIEW?

A LOT (1)

SOMEWHAT (2)

JUST A LITTLE (3)

NOT AT ALL (4)

6. WAS THERE ANY INDICATION OF CONFUSION OR PROBLEMS WITH MEMORY?

DEFINITELY YES (1)

SOME INDICATION (2)

JUST A LITTLE (3)

NOT AT ALL (4)

7. IN WHAT WAY? (e.g., TOPICS)

8. DID PATIENT HAVE ANY DIFFICULTY HEARING QUESTIONS?

YES, MUCH DIFFICULTY (1)

YES, SOME DIFFICULTY (2)

YES, JUST A LITTLE (3)

NOT AT ALL (4)

9. DID PATIENT HAVE ANY DIFFICULTY UNDERSTANDING (COGNITION) THE QUESTIONS?

YES, MUCH DIFFICULTY (1)

YES, SOME DIFFICULTY (2)

YES, JUST A LITTLE (3)

NOT AT ALL (4)

10. DID PATIENT HAVE ANY DIFFICULTY COMMUNICATING?

YES, MUCH DIFFIUCLTY (1)

YES, SOME DIFFICULTY (2)

YES, JUST A LITTLE (3)

NOT AT ALL (4)

11. DID PATIENT CRY DURING THE INTERVIEW?

YES (1)

NO (2)

12. THE QUESTION? THE TOPIC?

Mr/Mrs/Miss , again thank you very much.

You have been most helpful. There a few more questions I would like to ask you.

Would you mind if I were to come back and visit you, perhaps twice more in the next year? YES (1) NO (2)

APPENDIX E

In-Depth Interview Guide

The interview schedule provided a working tool which generated data on relevant topic areas listed below. While the interview schedule was utilised as a guideline, the interview was not confined within its parameters. Often a number of spontanenous questions were asked to pursue a line of inquiry that arose from the interview situation. This interviewing method has been described by Taylor and Bodgan (1982) as a recursive approach.

Topic Areas

A. Views about the move to the nursing home, and how this has affected their life
B. Views about what it is like to live in a nursing home
C. Views about family support before and since the move
D. Differences between the good old days and today's support for older people
E. Views about their future

APPENDIX F

Letter to Resident's Next-of-Kin

The Australian National University

The Research School of Social Sciences
Ageing and the Family Project
reference

GPO Box 4, Canberra, ACT 2601
Telegrams & cables NATUNIV Canberra
Telex AA 62694 SOPAC
Telephone 062-49 5111

I am a research scholar with the Ageing and the Family Project at the Australian National University. I have interviewed your , , and perhaps has mentioned my visit to you.

Let me explain to you the purpose of the study. The number of elderly Australians is increasing rapidly, yet there is very little information on the consequences of this demographic change, let alone its social and policy implications. To help overcome this knowledge gap, a research project on ageing was established in 1980 at the Australian National University in Canberra.

My study is concerned with older people entering and living in nursing homes and was chosen at random. I am attempting to identify the factors which influence the decision to obtain nursing home care. In particular, I would like to talk to you about your views on what motivated the decision to seek nursing home care, and the role family played in that decision. The study is aimed at improving the quality of services for the aged who are no longer able to live completely independently at home.

has kindly given time to discuss feelings about living at . As I am also trying to understand the views and concerns of families (or friends), I was also hoping that you might be able to spare me 30 minutes or so.

May I contact you to see if I can arrange a convenient time to interview you on the telephone? I have enclosed a return reply with an envelope, and I would be most grateful if you would indicate when it would be most convenient to call you. I would like to schedule a telephone interview sometime between to . Would you kindly indicate which day and time best suits you?

I would appreciate it if you reply at your earliest convenience.

We feel that our work can benefit present and future generations of older persons by improving government policies on the care of the aged, and increasing the public's awareness of the life experiences of older Australians.

If you have any questions, please feel free to write or call (062 49 3742 reverse charges). Your assistance and cooperation would be greatly appreciated.

Yours sincerely,

M. Victor Minichiello,
Research Scholar,
Ageing and the Family Project

PLEASE RETURN IN ENCLOSED

STAMPED ENVELOPE

Mr Victor Minichiello
NURSING HOME STUDY
Ageing and the Family Project
Research School of Social Sciences
Australian National University

Dear Mr Minichiello,

I agree to participate in your Nursing Home Study and be interviewed. My name is:

NAME: _____

ADDRESS: _____

_____

PHONE: ( ) _____

It would be convenient to contact me on:

DAY: _____

DATE: _____

TIME: _____ AM/PM

I understand that the information I give you will be strictly confidential and the information collected will be used only for academic purposes in the hope to improve the planning of services for the aged.

Yours sincerely,

APPENDIX G
Next-of-Kin Questionnaire

AUSTRALIAN NATIONAL UNIVERSITY

RESEARCH SCHOOL OF SOCIAL SCIENCES

AGEING AND THE FAMILY PROJECT

NEXT-OF-KIN INTERVIEW

Name of Respondent/Relationship

Name of Patient

Nursing Home Where Patient Lives

Date of Interview

Interview Began A.M./P.M.

Interview Finished A.M./P.M.

INSTRUCTIONS

GOOD MORNING _____. I AM VICTOR MINICHIELLO FROM AGEING AND THE FAMILY PROJECT OF THE AUSTRALIAN NATIONAL UNIVERSITY IN CANBERRA. AS MATRON _____ AND I EXPLAINED TO YOU IN OUR LETTERS, I AM STUDYING OLDER PEOPLE ENTERING AND LIVING IN NURSING HOMES.

I SPOKE TO YOUR _____, _____ ABOUT HOW HE/SHE CAME TO LIVE IN A NURSING HOME AND HOW HE/SHE FEELS ABOUT LIVING AT _____. AS I AM ALSO INTERESTED IN TALKING TO FAMILIES ABOUT WHAT THEY THINK OF OLDER PEOPLE LIVING IN NURSING HOMES, I WOULD LIKE TO TALK TO YOU ABOUT _____ MOVE TO _____.

BEFORE WE BEGIN, I WOULD LIKE TO REMIND YOU THAT ANYTHING YOU SAY TO ME WILL BE TREATED IN THE STRICTEST CONFIDENCE AND THAT YOU REMAIN FREE NOT TO ANSWER ANY QUESTIONS YOU PREFER TO EXCLUDE. THE INTERVIEW WILL TAKE A LITTLE OVER 25 MINUTES. DO YOU HAVE ANY QUESTIONS? YES/NO. AGAIN, THANK YOU FOR YOUR HELP. CAN WE BEGIN?

PART I

A. I WOULD LIKE TO KNOW MORE ABOUT _____,
MOVE TO _____.
I WOULD LIKE TO BEGIN BY YOU TELLING ME SOMETHING ABOUT WHERE
_____, LIVED JUST BEFORE HE/SHE
MOVED TO THE THIS NURSING HOME AND SOMETHING ABOUT HOW
YOUR _____ CAME TO LIVE AT THE _____
_____. (IMPORTANT PROBE TO DETERMINE
RESIDENTIAL PATHWAY TO THE NURSING HOME AND RECORD SUMMARY
STATEMENT OF WHAT THE RESPONDENT SAYS ABOUT THE ADMISSION
PROCESS).

PRIOR LIVING ADDRESS

1 PSYCHIATRIC HOSPITAL

2 HOSPITAL

3 OTHER NURSING HOME

4 HOSTEL

5 HOME WITH SPOUSE

6 HOME WITH CHILD

7 HOME WITH SIBLING

8 HOME WITH OTHER RELATIVE
(SPECIFY _____)

9 HOME WITH FRIEND

10 BOARDING HOME

11 HOME ALONE

LIVED THERE FOR HOW LONG?

_____(months)

_____(years)

ADDRESS PRIOR TO 1ST ADDRESS

1 PSYCHIATRIC HOSPITAL

2 HOSPITAL

3 OTHER NURSING HOME

4 HOSTEL

5 HOME WITH SPOUSE

6 HOME WITH CHILD

7 HOME WITH SIBLING

8 HOME WITH OTHER RELATIVE
(SPECIFY _____)

9 HOMW WITH FRIEND

10 BOARDING HOME

11 HOME ALONE

LIVED THERE FOR HOW LONG?

_____(months)

_____(years)

B. SUMMARY STATEMENTS FROM QUESTION A

PART II

COULD WE NOW TALK ABOUT _____ APPLICATION TO _____.

1. WHEN WAS THE DECISION TO MOVE TO _____, FIRST THOUGHT OF? (RECORD CIRCUMSTANCES PRIOR TO ADMISSION IF MENTIONED).

2. WHY WAS SUCH A MOVE CONSIDERED? (PROBE--WHY THEN AND NOT BEFORE?). (AGAIN RECORD CIRCUMSTANCES PRIOR TO ADMISSION IF MENTIONED).

3. NOW, IF YOU HAD TO MENTION THE THREE MOST IMPORTANT REASONS FOR _____ MOVING TO A NURSING HOME, WHAT WOULD THEY BE? (CHECK THE SELECTED ANSWER)

1 HEALTH PROBLEM (e.g., stroke)

2 INABILITY TO LIVE ALONE (e.g., unable to manage home, fearful)

3 GRADUAL PHYSICAL DETERIORATION INCREASING FRAILTY, OLD AGE (e.g., unable to do the things he/she use to do)

4 PLANNING AHEAD, GETTING SET IN ANTICIPATION OF FUTURE NEEDS

5 EXCESSIVE BURDEN ON FAMILY/CARER (e.g., daughter working, looking after children or sick husband, too much for carer to manage, family member working)

6 PATIENT WANTED TO BE INDEPENDENT FROM FAMILY (e.g., did not want family to fuss over him/her)

7 PRESSURE EXERTED BY FAMILY (e.g., family decided that patient needed nursing care attention and suggested move)

8 URGING BY PHYSICIAN, NURSE, SOCIAL WORKER

9 DISRUPTION OF LIVING ARRANGEMENT (e.g., death of spouse, fire)

10 SOCIAL ISOLATION OF PATIENT (e.g., loneliness)

11 OTHER _____

12 OTHER _____

13 OTHER _____

14 OTHER _____

4. (FOR EACH REASON MENTIONED ASK) NOW, WHY DO YOU THINK THIS WAS AN IMPORTANT REASON?

FIRST REASON _____

SECOND REASON _____

THIRD REASON _____

PART III

A NUMBER OF DIFFERENT INDIVIDUALS ARE OFTEN INVOLVED IN HELPING A PERSON TO MAKE THE DECISION TO MOVE.

1. WHO FIRST SUGGESTED THAT _____ MOVE TO _____. (RECORD FIRST NAME AND RELATIONSHIP).

   1. _____

   2. _____

2. WHAT OTHER PEOPLE HELPED _____ TO MAKE THE DECISION TO MOVE TO _____. (RECORD FIRST NAME AND RELATIONSHIP).

   1. _____

   2. _____

3. ANYONE ELSE? (RECORD FIRST NAME AND RELATIONSHIP)

   1. _____

   2. _____

4. WHO WOULD YOU SAY WAS MOST INVOLVED IN MAKING THE DECISION? (RECORD FIRST NAME AND RELATIONSHIP)

   1. _____

5. HOW MUCH OF A SAY DO YOU THINK _____
HAD IN MKAING THE DECISION TO MOVE INTO THE NURSING HOME.
WAS HE/SHE INVOLVED...

1. VERY MUCH
2. A MODERATE AMOUNT
3. VERY LITTLE OR NOT AT ALL

6. (IF 3 to QUESTION 5 ASK) WHY DIDN'T HE/SHE HAVE MORE OF
OF A SAY?

1. TOO ILL TO MAKE DECISION
2. DECISION IN THE HANDS OF OTHERS (DOCTOR, NURSE)
3. FAMILY DECISION
4. PATIENT WAS CONFUSED, DID NOT KNOW OF DECISION
5. _____
6. _____
7. _____

PART IV

NOW, I WOULD LIKE TO KNOW MORE ABOUT WHY THIS NURSING HOME
WAS CHOSEN AND HOW THE FAMILY FELT ABOUT _____
HAVING TO MOVE INTO THE NURSING HOME.

1. WHO TOLD _____ ABOUT _____?
(RECORD FIRST NAME AND RELATIONSHIP)

1. _____
2. _____

2. WHO FIRST CONTACTED THE MATRON? (RECORD FIRST NAME AND RELATIONSHIP)

   1. _____

   2. _____

3. WHO WAS MAINLY RESPONSIBLE FOR LOCATING THE NURSING HOME AND ARRANGING THE ADMINISTRATIVE DETAILS WITH THE MATRON AND DOCTOR? (RECORD FIRST NAME AND RELATIONSHIP)

   1. _____

   2. _____

4. WHY WAS _____ SELECTED?

   (RECORD ANSWER)

5. WHAT DID THE IMMEDIATE FAMILY THINK ABOUT _____ GOING TO LIVE IN A NURSING HOME? WAS THE FAMILY...

   1. VERY MUCH IN FAVOUR OF THE MOVE
   2. SOMEWHAT IN FAVOUR OF THE MOVE
   3. NEUTRAL
   4. SOMEWHAT OPPOSED TO THE MOVE
   5. VERY MUCH OPPOSED TO THE MOVE

6. WHY?

7. WHAT ABOUT _____, WHAT DID HE/SHE THINK ABOUT MOVING TO THE NURSING HOME? WAS HE/SHE...

   1 VERY MUCH IN FAVOUR OF THE MOVE

   2 SOMEWHAT IN FAVOUR OF THE MOVE

   3 NEUTRAL

   4 SOMEWHAT OPPOSED TO THE MOVE

   5 VERY MUCH OPPOSED TO THE MOVE

8. WHY?

9. DO YOU THINK IT WAS THR RIGHT DECISION FOR _____, COMING TO LIVE IN A NURSING HOME?

   1 YES

   2 NO

10. WHY?

PART V

1. DO YOU THINK MOVING TO THE NURSING HOME HAS CHANGED HOW _____, GETS ON WITH THE FAMILY?

    1. YES
    2. NO

2. IN WHAT WAY?

    1. POSITIVE
    2. NEGATIVE
    3. SAME

3. WHAT ABOUT WITH YOU?

    1. YES
    2. NO

4. IN WHAT WAY?

    1. POSITIVE
    2. NEGATIVE
    3. SAME

5. DO YOU THINK YOU SEE _____ MORE THAN, ABOUT THE SAME, OR LESS THAN WHAT YOU DID BEFORE HE/SHE MOVED TO THE NURSING HOME?

    1. MORE THAN
    2. ABOUT THE SAME
    3. LESS THAN

    WHY IS THAT? (RECORD ANSWER)

PART IV

1. IN GENERAL, HOW WAS _____ PHYSICAL HEALTH BEFORE HE/SHE MOVED TO _____. WOULD YOU SAY IT WAS...

   1 EXCELLENT

   2 GOOD

   3 FAIR

   4 POOR

2. AND FINALLY, IS _____ HEALTH NOW BETTER, ABOUT THE SAME, OR NOT AS GOOD AS IT WAS JUST BEFORE HE/SHE MOVED TO THE NURSING HOME?

   1 BETTER NOW

   2 ABOUT THE SAME

   3 NOT AS GOOD NOW

   8 DON'T KNOW/NOT SURE

PART V

1. DO YOU EXPECT _____ WILL MOVE FROM THE NURSING HOME?

   1 YES

   2 NO

2. WHY? (RECORD COMMENT)

AGAIN, THANK YOU FOR YOUR KIND HELP AND COOPERATION.

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